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Thesis

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Day service culture from the perspective of autistic adults with profound learning disabilities

A methodological development and empirical study in the space of autism and profound learning disability

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Thesis submitted for the degree of Doctor of Philosophy

The Open University

The Faculty of Wellbeing, Education and Language Studies

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Abstract

The primary purpose of this thesis is to explicate day service culture from the perspective of autistic people with profound learning disabilities. This includes their involvement in, and experience of, day service culture. Although other people such as support workers and autistic people without profound learning disabilities are also a significant part of day service culture, their perspectives were not the primary concern of this thesis. A review of the literature on service culture suggested that autistic people with profound learning disabilities shape and experience culture within the context of everyday life at day services, though it also recognised that there was minimal understanding of how to research such a topic. Therefore, a secondary aim was established: to detail a methodological approach that is ethically justified for researching the everyday experiences of autistic people with profound learning disabilities. This aim was initially addressed through a critical examination of what researchers mean when using the terms 'autism' and 'severe/profound learning disability' in relation to people with complex needs. It concluded that it is both epistemically and ethically unjustified to separate the terms when developing research, as this exacerbates the marginalised position of related people within academic and political domains. Subsequently, an academic space of 'autism and profound learning disability' is conceptualised using the phenomenological concept of life-conditions (Kraus, 2015) that recognises the shared material and immaterial circumstances of people with complex needs. A contribution to this space is made: an inclusive, lifeworld fractions approach (Ashworth, 2016) that can enable researchers to adapt studies in line with participants' perspectives and circumstances. This approach was subsequently used within a research study that addressed the initial aim of the thesis, through an investigation into the culture of a day service for autistic adults from the everyday, lifeworld perspective of 'Ben', an autistic adult with profound learning disabilities. The findings show everyday life to be guided by rich spatial and temporal customs that have developed over time through the pursuits and efforts of Ben and his peers. Those traditionally referred to as service users had created a community with rules and values that were congruent with their lifestyles and characters. These findings are indicative of the contributions that autistic people with profound learning disabilities make to the service cultures that they are part of, and demonstrates some of the ways in which they realise autonomy and independence in adulthood.

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Contents

Chapter One - Introduction

1.1 The Thesis.....	10
1.2 Day service provision.....	10
1.3 Study context.....	13
1.4 Personal context.....	14
1.5 Research aims and objectives.....	14
1.6 Notes on language.....	15
1.7 Thesis structure.....	18

Chapter Two – Literature Review: Day Service Culture

2.1 Search strategy.....	21
2.2 Defining service culture.....	22
2.3 A contemporary understanding of service culture.....	23
2.4 Service culture in research.....	25
2.5 The contributions of service people.....	29
2.6 Summary of service culture literature.....	33

Chapter Three - Literature Review: Defining Autism and Severe/Profound Learning Disability

3.1 An issue in developing a methodology with the term ‘autism and profound learning disability’	35
3.2 The medical model and its categorisations of autism and learning disability.....	37
3.3 Defining and differentiating autism and severe/profound learning disability.....	40
3.4 Exploring autism and learning disability according to the social model.....	45
3.5 The construction of personhood, narrative and challenging behaviour in the context of autism and severe/profound learning disability.....	48
3.6 Summary of ‘autism and severe/profound learning disability’	51

Chapter Four – Methodology

Part One – An Academic Space of Autism and Profound Learning Disability.....	52
4.1 An issue of representation.....	53
4.2 Evaluating the ‘ought’ of representing autism, severe/profound learning disabilities and complex needs.....	56
4.3 The practical implications of a space of autism and profound learning disability.....	60
4.4 The double empathy problem and inclusion phobia.....	62
4.5 Methodology part one summary.....	65

Part Two – Developing an Ethically Sensitive Methodology.....	67
4.6 Research context.....	67
4.7 Constructionism in the third space.....	68
4.8 A phenomenological direction.....	71
4.9 An approach for exploring experiences of everyday life.....	73
4.10 Lifeworld as in inclusive concept.....	75
4.11 Lifeworld fractions and bricolage.....	78
4.12 Thinking phenomenologically while doing phenomenology.....	80
4.13 A summary of the chapter and the proposed methodology.....	84
Chapter Five – Methods	
5.1 Negotiating a favourable ethical opinion.....	87
5.2 Use of language henceforth.....	88
5.3 Establishing a research site, recruitment and seeking consent.....	89
5.4 The background of Ben and the day service.....	94
5.5 Consideration for further participants.....	95
5.6 A former connection with the fieldwork site.....	96
5.7 Potential benefits and risks.....	98
5.8 Stage 1 – Fieldwork methods – Participatory observation.....	101
5.9 Support worker co-researcher participatory observation.....	104
5.10 Ethnographic ‘hanging out’.....	105
5.11 Stage 1 – Data Analysis – Nvivo 11.....	108
5.12 Lifeworld Fractions.....	109
5.13 Lifeworld Ontology – Sociality, selfhood, project.....	113
5.14 Temporality and spatiality.....	115
5.15 Summary: Stage two lifeworld fieldwork direction.....	117
5.16 Analysis of the phenomenon of everyday life at day support services.....	118
5.17 Sociality.....	119
5.18 Stage 2 – Fieldwork methods.....	121
5.19 Stage 2 – Lifeworld Analysis.....	122
5.20 Stage 2 – Analysis of the phenomenon of everyday life at day support services.....	123
5.21 Stage 3 – Fieldwork methods.....	124
5.22 Fieldwork Summary.....	127

5.23 Reflecting on trustworthiness.....	128
5.24 Methods – Analysis.....	130
5.25 Methods – Analysis of Ben’s experiences of everyday life at day support services.....	133
5.26 Methods – Analysis of what characterises everyday life at day support services as a phenomenon.....	137
5.27 A Summary of the Methods Chapter.....	139
Chapter Six – Findings	
Part One – Ben’s Lifeworld.....	142
6.1 The contextual shifting of identity.....	142
6.2 The supported.....	142
6.3 The supporter.....	144
6.4 The Independent.....	146
6.5 The Partner.....	149
6.6 A visceral world.....	151
6.7 Feeling the environment.....	151
6.8 Guarding the body in a social culture.....	154
6.9 Living the future through the past.....	156
6.10 Preparation.....	156
6.11 Belonging in time and space.....	160
Part Two – Everyday Life at the Day Service.....	162
6.12 Spatial customs.....	162
6.13 Space management.....	162
6.14 Ways of inhabiting space.....	171
6.15 The routine of daily life.....	176
6.16 A sense of risk.....	183
6.17 The creation of risk.....	183
6.18 A place to learn; a place to teach.....	188
6.19 Teaching and learning in the Hall.....	188
6.20 Teaching to create community.....	191
6.21 A summary of the findings.....	194
Chapter Seven – Discussion: Service Culture and Place Ballet and the Possibility of At-homeness	
7.1 At-homeness.....	196
7.2 Rootedness.....	198

7.3 Appropriation.....	200
7.4 Regeneration.....	202
7.5 At-easeness.....	203
7.6 Warmth.....	205
7.7 At-homeness: an aim for harmonious day services cultures.....	206
Chapter Eight - The <i>While</i> of Participation	
8.1 The <i>while</i> of participation.....	209
8.2 The <i>while</i> of participation – dialogue.....	210
8.3 The <i>while</i> of participation – analysis.....	212
8.4 The <i>while</i> of participation - design.....	213
8.5 Summary of the <i>while</i> of participation.....	214
8.6 Reflecting on the methodology as inclusive, participatory, emancipatory, or something else.....	215
Chapter Nine – Conclusion	
9.1 Day service culture – contributions.....	218
9.2 Day service culture – implications.....	221
9.3 Day services culture – limitations.....	222
9.4 Methodological development – contributions.....	224
9.5 Methodological development – implications.....	226
9.6 Methodological development - limitations.....	227
9.7 Thesis conclusion.....	228
Reference list.....	230
Appendices.....	245

Tables and figures

Figure 1: Example of Nvivo lifeworld analysis.....	109
Figure 2: Lifeworld fractions within Nvivo.....	110
Figure 3: Units of meaning within Spatiality fraction.....	112
Figure 4: ‘The Hall’ Fieldmap example.....	125
Figure 5: Example of completed fieldmap.....	126
Figure 6: Fieldmap, 15 th July, 9.40 AM.....	134
Figure 7: Screenshot of candidate theme ‘Living the future through the past’ within Nvivo.....	135
Figure 8: An example of a thematic map of the ‘Feeling sensory environment’ candidate theme during phase 4 of analysis.....	136
Figure 9: Fieldmap depicting Ben sitting separately from his support worker.....	148
Figure 10: A fieldmap that illustrates a support worker instructing another to move out of Ben’s space as he arrives.....	158
Figure 11: A fieldmap showing person who consistently sits in the far corner of the Hall.....	163
Figure 12: Three fieldmap sections depicting support workers freeing up Ben’s area.....	164
Figure 13: Fieldmap section.....	165
Figure 14: Section of fieldmap showing two persons who share in the same space while moving (arrows depict walking)	166
Figure 15: Section of fieldmap depicting inhabitant laying down talking aloud.....	167
Figure 16: Fieldmap illustrating an inhabitant requesting drinks.....	168
Figure 17: Fieldmap extract depicting a support worker managing space.....	170
Figure 18: Fieldmaps depicting inhabitant movement with arrows.....	171
Figure 19: Fieldmap section showing person singing and another jumping on spot.....	174
Figure 20: Fieldmap showing the lack of reaction from an inhabitant who lays next to a large crash.....	175
Figure 21: Two fieldmaps showing the gathering and chatter of support workers in mornings.....	178
Figure 22: Extract of fieldmap showing routine interaction, movement and activity of inhabitant.....	180

Figure 23: Fieldmap showing support worker instructing another to assess mood of inhabitant before leaving Hall.....	184
Figure 24: Fieldmap showing an inhabitant arriving, strolling through the main Hall while hand their lunch to a support worker.....	187
Figure 25: Fieldmap showing agency support workers sitting separated in the top left corner reading inhabitant folders, while inhabitants and service support workers sit and talk at the other end of the Hall.....	192
Figure 26: Fieldmap showing Ben controlling his personal area.....	200
Figure 27: Fieldmap (16 July, 11:40 p.m.) depicting two inhabitants who walk regularly.....	203
Figure 28: The Hall.....	214

Chapter One – Introduction

1.1 *The thesis*

The purpose of this thesis is twofold: first, to present an investigation into day service culture through the everyday experiences of autistic adults with profound learning disabilities. Second, to develop and demonstrate an ethically sensitive methodological approach for exploring the experience of autistic people with profound learning disabilities, namely those who primarily communicate through vocalisations and body language. The research did not begin with this second aim, however, the process of conducting a literature review highlighted the distinct need to consider the implications of epistemological stances and methodological approaches when working with people that may be identified within this group. Largely, this is due to research practices that have situated them as ‘voiceless subjects’ (Mietola, Miettinen, & Vehmas, 2017, p. 264), understood as incapable of contributing their own perspectives and thus garnering minimal consideration from researchers contributing methodological developments. As such, it is not just that the voices of autistic people with profound learning disabilities are generally absent from research, but that the tools with which to create and conduct research exclude their participation. The ways to research with autistic people with profound learning disabilities are, as Simmons and Watson (2014b, p. 148) state, ‘the most underdeveloped in methodological terms of all social science research.’

A research field that is absent of the voices of autistic people with profound learning disabilities suggests a social care landscape that is also absent of their perspectives, as the former guides the latter through the development of policy and practice (Cluley, Fyson, & Pilnick, 2020, p. 251; Robinson & Graham, 2020, p. 3). This is disconcerting as the complex needs of related people mean that their lives are often guided by a social care system designed without their input, from everyday factors such as the training that influences how support workers act and communicate, to broader issues such as how social care is funded (Pellicano, 2017b, p. 32). Acknowledging this, the primary goal of this research is to investigate the experiences related to a key feature of the adult social care system in the context of autistic people with profound learning disabilities, that of the day service.

1.2 *Day service provision*

After the gradual closure of large scale institutions in the 1980s, ‘day centres’ emerged across local communities within the UK, aimed at providing vocational and recreational activities for people with learning disabilities (Walmsley & Johnson, 2003, p. 48). Since then, day centres have developed in line

with the publication of key learning disability and autism strategies, *Valuing People* (Department of Health, 2001), *Valuing People Now* (Department of Health, 2009), and *Fulfilling and reward lives* (Department of Health, 2010), which each promote the need for independence, choice and community inclusion for autistic people and people with learning disabilities. Furthering the development of day centres was the adoption of personalisation as a primary focus of the UK's social care agenda (see National Voices, 2014), which refers to 'the means by which people who access care services, whether statutory or self-funded and in all care settings, can shape them to suit their personal needs' (Morgan, 2010, p. 14). What this has meant is the evolution of 'day centres' into 'day services': a contemporary model of Monday to Friday support provision that uses one or more buildings as a base for a service organisation, but where support, activities and occupations extend out from those buildings into regional community spaces and facilities. Depending on a person's preferences, day provision may mean accessing a service's base throughout the week, for part of the week, or not at all, and can encompass aspects of 'day support' (from a centre), 'outreach support' (within community/local settings) and 'home support' (from a person's home). As The Health Foundation reported recently, adults with learning disabilities and autism aged between 18-64 are now 'the largest group receiving local authority support' in England, with approximately 50,000 receiving support from day service organisations (Idriss, Allen, & Alderwick, 2020).

In 2010, Mansell (2010) found that *Valuing People* (Department of Health, 2001) had resulted in positive developments in day service provision for people with 'profound intellectual and multiple disabilities' (including autism), though concluded that there was still much progress to be made, with many people within this group not having their needs met. For example, Mansell (2010) referred to a survey (PMLD Network, 2006) of families of people with profound learning disabilities in which only 3% of respondents believed there to be adequate adult service provision. Supporting these views was research by Vlaskamp, Hiemstra, Wiersma, and Zijlstra (2007) that examined what adults with profound intellectual and multiple disabilities did while at day service provision, finding that 58.1% of their time was spent doing nothing, or as suggested by some participating service staff, soaking up the atmosphere. Mansell (2010) argued that to develop better service provision, there was a need to facilitate positive relationships between staff and those they support, to facilitate individualised support approaches, to value family member perspectives, and to provide sustained support packages.

In the years after Mansell's report, one of his key recommendations, to sustain packages of care, could be seen to be challenged, as day service provision faced significant cuts with a third of local authorities reported to have closed day services (Mencap, 2012). During this period, exposés on assessment and treatments units within the UK revealed institutionalised, abusive and dehumanising

practices involving autistic people with profound learning disabilities, such as in the Winterbourne (Department of Health, 2012) and Whorlton Hall (see Murphy, 2019) scandals. To prevent future incidents of abuse, the Transforming Care agenda (Transforming Care and Commissioning Steering Group, 2014) has emphasised the need for high-quality community based services, including autism and learning disability day services. More recent analysis (Hatton, 2017) has however, indicated that many autistic people with profound learning disabilities are still contained within assessment and treatment units, suggesting, as many point out (Beadle-Brown, Beecham, Leigh, Whelton, & Richardson, 2021; Hoghton & Lamb, 2019; Murphy, 2019; Richards, 2020; Willis, 2020), that there continues to be a lack of quality day service provision to meet the needs and demand of this population.

The Care Quality Commission (CQC, 2016) has identified the development of positive service cultures as being key to meeting the need to improve social care provision in England. Service culture refers to the practices, views and values that exists within service organisations, and are shown to have significance as they guide the actions and approaches of support practitioners (Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012). Cultures develop and exists in day services as a way of responding to, and coping with, day-to-day events and circumstances (Schein, 1985). They are therefore unique to service organisations, reflecting and containing the views and customs that, over the course of time, they have embedded into their ways of working.

For many autistic people with profound learning disabilities, day services represent the sites at which they orientate their Monday-to-Friday, everyday lives. It is the base from which they, alongside their peers, pursue their interests, hobbies and aspirations. The cultures that develop and exist within day services are therefore fundamental to the ways in which autistic people with profound learning disabilities experience adulthood, forming and representing the customs and practices inherent in a shared community. In exploring the literature in the second chapter, it is recognised that service culture develops and exists through contributions from three key, interrelating groups: people that access services, people that are employed by services, and people that guide service practice, such as researchers or policy makers. Positive services cultures are understood to be ones in which the views and values of these three groups are harmonious, as practices and customs develop to address their individual outlooks and occupations (Felce, Lowe, & Jones, 2002). As culture exists under the surface, 'infused with symbols and symbolism' (Druckman, 1997, p. 69), so too do contributions, forming through the everyday interactions and activity of day service life. The service culture literature has explored this through the scope of the latter two aforementioned contributing groups, and so it is the focus on the contributions of autistic people with profound learning disabilities that distinguishes this research as novel and necessary.

1.3 *Study context*

The study detailed in this thesis took place at a day service for autistic adults with and without learning disabilities (aged 18 and over). The service organisation is a local charity based in the north of England. It has two day services and also provides support through outreach work and home support. Autistic adults of diverse personalities, circumstances, abilities and support needs attend the day service, pursuing interests and occupations through individual schedules. Some are part of its everyday activity, arriving in the mornings and participating in life in and outside of the day service space and using its facilities, such as the garden, kitchen or art room. Other people merely use it as a meeting place, connecting there with their support workers before travelling to local areas and destinations according to their plan for the day.

As the research aimed to explore service culture from the perspective of autistic adults with profound learning disabilities, a significant part of the study involved researching with a person named Ben (pseudonym) who attended the day service Monday-to-Wednesday each week. Ben was 27 years old at the time of the research and had been part of day service life for much of his adult life. He primarily communicates through vocalisations and body language and has a support worker accompany him throughout his day-to-day pursuits. The focus on a single participant was for two reasons (these are explained in more detail in Chapter Five): first, to understand the meaning of Ben's communication required me to learn about it across many contexts and environments and through repeated encounters (see also Gaudion, 2015; Goode, 1994; McCormack, 2017; Mietola et al., 2017; Simmons & Watson, 2014b). Second, the methodology involved a time intensive, cyclical process of fieldwork and analysis that explicated Ben's experiences of everyday life from a phenomenological perspective. This approach, however, did not limit the research to viewing everyday life from only Ben's perspective, for it was designed to learn of the shared ways Ben and his peers experienced everyday life, so that methods could be introduced that were relevant to this shared perspective. This meant considering on-going findings of Ben's experiences in relation to a broader exploration of day service life, with the process highlighting the importance of space and time within everyday practices and experiences. The result was the introduction of a novel method that documented the roles, contributions and experiences of Ben and other autistic people with profound learning disabilities at the day service, as well as those people they shared it with. The research was, therefore, an exploration of everyday life at the day service, the site of culture and its development, from the perspectives of autistic people with profound learning disabilities.

1.4 *Personal context*

As a support worker of ten or so years, I met and spent many hours, days and weeks with autistic people with profound learning disabilities, each with their own character, interests and eccentricities. They shaped my early adulthood and consequently who I am today. After leaving support work to pursue an academic interest in autism, I was confronted, wholeheartedly, with dismay at the representations of autistic people with profound learning disabilities in research, as well as the apparent exclusion of their voices and perspectives. The idea that it was too difficult to access their views was baffling as I, and so many other support workers could attest to, sought their perspectives as part of any normal every day. This PhD study thus began with a simple aim to research the experiences of autistic people with profound learning disabilities within day services, though as mentioned in the beginning paragraph, I learned that this was not so simple, as methodologies, methods and tools had generally developed without consideration for how related people may participate in research (Simmons & Watson, 2014b, p. 148). There were researchers in both the autism (e.g. Ridout, 2017) and learning disability (e.g. Mietola et al., 2017; Simmons & Watson, 2014b) fields proposing methodologies or approaches that were relevant to people with complex needs within the respective populations, yet it was unclear as to why one might be beneficial over another, or why related people were separated in such regard. And so the search for answers began and an unexpected twist in the study occurred, as methodological considerations became a second research aim.

1.5 *Research aims and objectives*

This research has two key *aims*:

1. To investigate day service culture from the perspectives of autistic adults with profound learning disabilities.
2. To develop an ethically sensitive methodology for exploring the experiences of autistic people with profound learning disabilities.

In relation to these two aims, there are a number of *objectives*:

In relation to day service culture, the objectives are:

1. To explore service culture, specifically in relation to day services, in order to establish current understandings of its role in relation to the lives of autistic people with profound learning disabilities.

2. To explore the day service experiences of an autistic person with profound learning disabilities, so that these can be related to the service culture that they are part of.
3. To investigate the role of the everyday within day service culture: specifically, to examine the customs and contributions of an autistic person with profound learning disabilities, as well as their peers, and to contextualise these within the wider context of day service life.
4. To situate the everyday practices and experiences of autistic people with profound learning disabilities within a broader understanding of day service culture, that which includes the cultural contributions of service people, support workers, and formal authorities (e.g. managers, researchers and policy makers).

In relation to developing a methodological approach, the objectives are:

5. To establish ethically sensitive ways of developing research for autistic people with profound learning disabilities.
6. To establish ways of researching that are sensitive to the values and perspectives of autistic people with profound learning disabilities. This includes bringing together the values espoused by their related communities: that of the autistic community, and people with learning disabilities.
7. To develop a methodology that can be used to conduct research with autistic people with profound learning disabilities in ways that are sensitive and appropriate to their communicative styles, lifestyles and circumstances.
8. To develop a methodology that can explore phenomena through the experiences of autistic people with profound learning disabilities.
9. To develop a methodology that enables a practical research process in which autistic people with profound learning disabilities can meaningfully participate, and, where possible, shape according to their perspectives, such as in the choice of research methods and their focus.

1.6 Notes on terminology

On the population: The term ‘complex needs’ refers to people who ‘require a high level of support with many aspects of... daily life, and rely on a range of health and social care services’ (Think Local Act Personal, 2020). The terms ‘autism’ and ‘profound learning disability’ are clarified in detail in the second part of the literature review - part of the initial methodological development. However, to briefly state its conclusions: the terms autism and severe/profound learning disability in relation to people with complex needs represent the divergent paths of two research fields, and not the separate states of two ontological groups. In other words, there is no reliable method with which to distinguish autism and severe/profound

learning disability from severe/profound learning disability alone, and the separation of the terms only serves to further marginalise those people labelled as such (see Chapter 4.1). The term ‘autism and profound learning disability’ will therefore be used to refer to people with complex needs that may be considered in relation to the terms ‘autism’, ‘severe learning disability’ and ‘profound learning disability’. It is argued in Chapter four that using this terminology can help to bring greater attention to the collective of perspectives and voices of people related to autism and profound learning disability. When referencing research through the thesis, the terms used by the cited authors will be chosen as this is useful for representing their constructions within different academic communities.

On community language: First, in line with recommendations by Gernsbacher (2017) and Bottema-Beutel, Kapp, Lester, Sasson, and Hand (2020), and preferences of people within the autism community (Kenny et al., 2015), this research adopts identity-first language in reference to autism as it is contended that it reduces stigma. As such, the term ‘autistic people’, as opposed to ‘people with autism’, is used throughout the thesis. Second, the term ‘learning disability’ rather than ‘intellectual disability’ has been chosen, as research by Cluley (2018) has suggested that people within the United Kingdom (UK) – the location of this study - find it easier to understand. Moreover, it is the term most commonly adopted within research conducted by, or in partnership with, people with learning disabilities (e.g Brownlee-Chapman et al., 2018).

On service person language: Through chapters one to four, the term ‘service people’ is used in relation to those people that access services, and that are supported by support workers, often referred to as ‘service users’. This latter term, argues Lloyd (2008), fails to acknowledge the contribution that is made by people who access services and leads those in positions of power – managers, health and social care professionals, staff - to undervalue their perspectives. It is argued that in comparison to ‘service users’, the term ‘service people’ acknowledges to a greater degree the participation and involvement of such people in creating day service life. As the thesis moves into the analysis stages, this term once again changes – a result of conducting fieldwork and subsequently closely examining all that I had collected. From this position, the research showed the power relations of daily life within the day service to be complex, often with those termed ‘service users’ leading the way. Their lives and personalities are at the centre of the way it operates and many have dedicated years of their life to making it is what it is (many more than most members of staff). This is a community connected in space in which people *live* - that is *live* in a phenomenological sense (they do not reside there), in that they are people that share in the events of everyday life, present and part of one another’s lifeworlds (Berndtsson, Claesson, Friberg, &

Öhlén, 2007). And so, for this reason, I adopt the term ‘inhabitant(s)’ – meaning ‘one that occupies a particular place regularly, routinely, or for a period of time’ (Merriam-Webster, 2019) - to describe those that would otherwise be referred to as service users or service people. To note, the term inhabitants is not adopted from the start because the term refers to those people that shape and are part of day service cultures, while the earlier chapters reference literature relating to diverse contexts – services, schools and so forth – to which the term may not be appropriate.

On methodology terms: As discussed in the literature review and methodology chapter, a commitment to seeking the perspectives of autistic people with profound learning disabilities, and the process of developing an appropriate methodology, situated this study within an inclusive framework. On the one hand, ‘inclusive research’ is seen within the learning disability field as an umbrella term that covers a number of qualitative methodologies that involve active roles for participants, such as emancipatory or participatory research; however, people with learning disabilities have voiced a preference that *all* inclusive methodologies be termed inclusive research, as this has a clearer statement of intent (Seale, Nind, Tilley, & Chapman, 2015, p. 488). Thus, adopting the term ‘inclusive research’ in place of other terminologies could be seen as an initial step in developing accessible research opportunities for people with learning disabilities. On the other hand, the term ‘participatory research’ is frequently becoming adopted in the autism field as an approach to increase autistic voice within research, while ‘inclusive research’ has been adopted by Chown et al. (2017), a group of autistic researchers, to define a set of guidelines with which to carry out participatory or emancipatory autism research. Although only a slight difference, research with autistic people with learning disabilities that claims to be ‘inclusive’ or ‘participatory’ may be understood differently by the learning disability community and the autistic community. In the context of this study, the extent to which it could be considered participatory is debatable from both learning disability and autism research perspectives, yet it has been developed to fulfil an essential feature of any inclusive research: for the researcher to give precedence to the participants’ voices and perspectives (Nind & Vinha, 2014). For this reason, the term ‘inclusive’ is used to refer to the study’s overall stance, though it is not claimed that it adheres to the inclusive autism framework put forward by Chown et al. (2017). The implications of this stance are thoroughly explored in the methodology chapter.

1.7 Thesis structure

Chapter One - Introduction

The aims of the research are presented. Terminology use is outlined. The research is given context in relation to day services and their roles during the early adulthood of autistic people with profound learning disabilities.

Chapter Two – Literature Review: Day Service Culture

This literature review explores contemporary understandings of day service culture. It identifies how service culture develops through the domains of formal and informal cultures. The impact of service culture on different aspects of day service life is considered in relation to the wider service literature. A clear gap in knowledge is located relating to the perspectives and contributions of service people, with no current understandings of the roles of autistic people with profound learning disabilities in day service cultures.

Chapter Three – Literature Review: Defining Autism and Severe/Profound Learning Disability

In order to address the gap in knowledge established in chapter two, that relating to the roles of autistic people with profound learning disabilities in day service cultures, this chapter makes the first step towards understanding how to undertake research on such a topic. This first step concerns a key aspect of developing any empirical study: to detail who the intended population is, which, in the case of this research, is ‘autistic people with profound learning disabilities’. To do this, a literature review explores the terms of ‘autism’ and ‘severe/profound learning disability’ to establish foundational epistemic assumptions. This involves an in depth investigation of the terms through the two dominant models of disability – the social and the medical. The findings suggest there is no epistemic reason to separate the terms of ‘autism’ and ‘severe/profound learning disability’ when developing research for related people with complex needs.

Chapter Four – Methodology

Part One – An Academic Space of Autism and Profound Learning Disability

This chapter begins with an exploration of the ethical implications of converging or separating the terms of ‘autism’ and ‘severe/profound learning disability’. This is done through a consideration of who represents related people within academic, social and political life. Drawing from the literature review, it is proposed that it is both epistemically and ethically unjustified for the terms to continue to be considered in separate academic domains, and so an academic space of ‘autism and profound learning disability’ is

proposed. The practical and ethical implications of such a space are subsequently explored through the critical and inclusive research fields of autism and learning disability.

Part Two – Developing an Ethically Sensitive Methodology

Drawing from the exploration of the practical and ethical implications of research within the space of autism and profound learning disability, a discussion on epistemology and ontology provides the first building blocks for a methodology that can explore service culture from the perspectives of autistic people with profound learning disabilities. This methodological development guides a review of the approaches and theory of phenomenology, as well as references to and consideration of inclusive autism and learning disability research, and consequently a novel methodology is proposed.

Chapter Five – Methods

The ethics of this research is discussed with reference to its potential risks and benefits for participants. This is subsequently contextualised with a description of the participant recruitment process. As the methodological approach is novel in concept, involving an on-going development of methods in relation to fieldwork, periods of analysis and emerging theory, the methods are discussed in detail in order to demonstrate the process. This also helps to inform later discussions around the applicability of the methodology for involving autistic people with profound learning disabilities in research. To close, the final analytic process is described.

Chapter Six – Findings

Part One – Ben's Lifeworld

Three themes and their related subthemes are presented that describe everyday life within day services as experienced by the study participant, Ben: first, *Living the Future through the Past* considers Ben's temporal experiences at the day service and the sense of security that exists in the environments, people and activity of his past. Second, *A Visceral World* explores Ben's embodied experiences, looking at how he feels his day-to-day environments, and how his etiquette helps to manage sensory experiences within a social world. Third, *The Contextual Shifting of Identity* details how Ben experiences himself and others across the different circumstances of day-to-day life at the day service.

Part Two – Everyday Life at the Day Service

Four themes are presented that describe the phenomenon of everyday life within the study day service: first, *The Routine of Daily Life* details the unwritten schedules that guide the activity and actions of people at the day service. Second, *Spatial Customs* explores the ways in which environment and space are distinct parts of everyday life, embedded with values and customs that organise the people of the day service.

Third, *A Sense of Risk* describes the ways in which the day service houses both safety and risk and how this comes to be experienced by support workers and inhabitants. Fourth, *A Place to Learn; A Place to Teach* shows everyday life to be characterised by a process of learning and teaching that is facilitated by both inhabitants and support workers and that maintains a sense of community within the day service.

Chapter Seven – Discussion: Service Culture and Place Ballet and the Possibility of At-homeness

This discussion considers the study findings in the wider context of day service culture. It details how particular aspects of service culture may affect day-to-day life within day services, but also how day-to-day life may affect aspects of service culture. The implications of this on the experiences of autistic adults with profound learning disabilities are explored through the phenomenological concept of ‘at-homeness’ (Seamon, 1979, p. 70).

Chapter Eight – Discussion: The *While* of Participation

This discussion reflects on the methodology that was developed for this study, namely how its theoretical perspective came to be realised when conducting research. It explores the practical ways in which the participant contributed to the research through three areas termed ‘dialogue’, ‘analysis’ and ‘design’, using the concept of the ‘while’ (Heidegger, 1996) to assess their participation and what it meant for the research.

Chapter Nine – Conclusion

The thesis concludes by evaluating how the research has addressed its two key aims – to explore day service culture from the perspective of autistic people with profound learning disabilities, and to develop a methodology that is ethically justified in exploring the experiences of autistic people with profound learning disabilities. Both aims are addressed through references to the contributions, implications and limitations of the research.

Chapter Two - Literature Review

Part One – Day Service Culture

This chapter seeks to address the first objective of the research: to examine current understandings of day service culture in relation to the lives of autistic people with profound learning disabilities. It begins by detailing a search strategy used to locate relevant literature. Subsequently, a definition of service culture is provided by examining the way understandings have developed in relation to wider organisational culture research. This is followed by a review of knowledge of service culture in a contemporary context, with specific reference to the cultures of services providing support to autistic people and people with learning disabilities. Consideration is given to how service culture may affect particular aspects of service processes, such as staff training and practice, and this is outlined through a discussion on relevant research. Finally, the role of service people within service culture is examined.

2.1 *Search strategy*

The aim of this literature review was to investigate contemporary understandings of service culture within day services for autistic adults with profound learning disabilities. The focus on contemporary understandings reflects not only a need to establish an up to date knowledge of service culture, but also the acknowledgement of a developing social care landscape (see Šiška & Beadle-Brown, 2020) in which services are adapting to the tenets of personalisation and its emphasis on community inclusion (see Morgan, 2010). As such, day services in this context refers to any service organisation that provides support to autistic adults with profound learning disabilities on a Monday-to-Friday basis. That is to say, some organisations provide more than one type of support, such as support from a building with day-to-day facilities, outreach support in local communities, support at and from people's houses, or a mix of these. It may also be the case that a service provides support to autistic adults with profound learning disabilities, as well as autistic adults without learning disabilities, or with less complex needs.

The following sources were searched (in alphabetical order):

- Databases: SAGE; Taylor & Francis Online; Wiley.
- A hand search of key journals: Autism; Autism in Adulthood; British Journal of Learning Disabilities; The Critical Journal of Interdisciplinary Autism Studies; Disability & Society; Forum: Learning Disability Quarterly; Journal of Intellectual & Developmental Disability; Journal of Applied Research in Intellectual Disabilities; Tizard Learning Disability Review.

Combinations of keywords and corresponding boolean operators:

- autism* OR asc OR asd OR severe autism OR learning disabilit* OR profound learning disabilit* OR severe learning disabilit* OR intellectual disabilit* OR profound intellectual disabilit* OR severe intellectual disabilit*
- day service* OR day support service* OR service*
- culture OR service culture OR organisational culture

The search terms were chosen to reflect those most commonly used in England, the location of this study. Another aim was to identify service culture research concerning autistic people *with* profound or severe learning disabilities, so selected were terms that could identify research that included people with both diagnostic labels. The search terms did however, also account for and identify research concerned with people with only one diagnostic label or the other, as well as other closely linked diagnostic terms, for example the term ‘profound learning disabilit*’ identified papers that used the term ‘profound and multiple learning disabilities’. The search covered published studies from January 2010 – June 2020 in order to account for developments in social care since the publication of a key framework for autism services in England: ‘Fulfilling and reward lives: the strategy for adults with autism in England’ (Department of Health, 2010). The search terms were also used as weekly Google Scholar alerts from December 2018 – June 2020. References within identified papers were scanned to identify other relevant publications, and this accounts for papers included that were published prior to 2010.

No papers were identified that specifically explored service culture within day services for autistic people with profound learning disabilities. Therefore, the selection criteria was broadened to include:

- Research relating to service culture in general, such as services that provide support to people at their homes (as opposed to specifically day service culture).
- Research that focused on people only in relation to the diagnosis of autism, or only in relation to diagnosis of learning disability (as opposed to autism *and* learning disability).

2.2 Defining service culture

The finer details of the term ‘organisational culture’ are contested by scholars (see Bellot, 2011) though a commonly adopted definition is:

The pattern of basic assumptions which a given group has invented, discovered or developed in learning to cope with its problems of external adaptation and internal integration, which have worked well enough to be considered valid, and therefore to be taught to new members as the correct way to perceive, think and feel in relation to those problems . . . it is the assumptions which lie behind values and which determine

the behavior patterns and the visible artifacts such as architecture, office layout, dress codes, and so on (Schein, 1985, p. 2).

Organisational culture is a complex subject (Bellot, 2011, p. 30) that exists under the surface, 'infused with symbols and symbolism' (Druckman, 1997, p. 69). There is consensus among scholars that organisational culture is owned by the related organisation, as opposed to something the organisation is, and, therefore, it can be controlled, influenced or changed by its members (Bellot, 2011, p. 31). Organisational culture is specific to individual organisations and continually developing. According to this, day service cultures can broadly be understood as unique (see also Wood et al., 2014) evolving entities, that are subject to the ways in which those people part of them – service people, support workers, managers and so on – adapt as a group to manage the various demands of everyday life. Simply put, 'it is the way we do things around here' (Deal & Kennedy, 1983, p. 4).

As organisational culture research predominately examines corporate enterprises, the methods used within this field have been questioned in the context of health and social care settings (Bellot, 2011, p. 35). The need to distinguish methodological approaches for research into services culture has however, received little attention. Instead, researchers have often used approaches traditionally designed to examine corporate culture; for instance, Humphreys, Bigby, Iacono, and Bould (2019, p. 2) notes two studies (Gillett & Stenfert-Kroese, 2003; Hatton et al., 1999) that utilised generic tools to examine organisational culture in learning disability services providing support at houses, finding inappropriate questions relating positive culture to staff competitiveness. In one such question, staff were rated on how aggressive their practice was, demonstrating a link clearly suggestive of aims relevant to corporate culture, though with little regard to how support workers may build positive relationships with service people. Bigby, Knox, et al. (2012, p. 453) also noted that tools for assessing staff practice had not developed since their use in institutions (Pratt, Luszcz, & Brown, 1980), and that there was a tendency to focus on particular aspects of organisational culture, such as staff decision making (e.g. Dunn, Clare, & Holland, 2010), without consideration for how wider contexts impact staff and those who they support.

2.3 A contemporary understanding of service culture

Two organisational culture concepts relevant to disability services remained underused for many years: the cultural domains of the formal and informal (Felce et al., 2002; Hastings, Remington, & Hatton, 1995). The formal concerns processes controlled by management and outside influence, such as government policy, and this relates to staffing, job roles, funding, training, working practices and organisational policies (Humphreys et al., 2019). Informal culture recognises that staff work with their own individual 'values,

motivations, competencies and interests' (Felce et al., 2002, p. 390), and that through experiences in a group setting, these amalgamate into shared ways of working. Disharmony between the informal and formal means a service culture as a whole falls into disarray, leading to staff practice that is incongruous with formal requirements of the role. For example, in a service providing support to people with profound learning disabilities, Charnley, Hwang, Atkinson, and Walton (2019) evidences cultural disharmony, finding that support workers understood that they were formally required to facilitate individual leisure activities for those they supported though this type of one-to-one work was regarded as dangerous; instead, 'in learning to cope with its problems' (Schein, 1985, p. 2), the support worker team commonly used group activities.

In part of an inclusive project examining the effect of deinstitutionalisation in Australia (see also Bigby, Cooper, & Reid, 2012; Bigby & Frawley, 2010), Bigby, Knox, et al. (2012) drew from the concepts of the informal and formal and took the first step to empirically conceptualising organisational culture within learning disability services. Their aim was not to specifically focus on the formal or informal, but to investigate the complexities of both to understand culture as a whole in relation to a service that provided support in five houses inhabited by 26 people with severe learning disabilities. The authors argued that many could also be considered autistic, though this was not formally recognised (Bigby, Knox, Beadle-Brown, & Clement, 2014, p. 286). An ethnographic approach was adopted to explore everyday events and processes, with participant observations including both the people with learning disabilities and their support workers. In the context of the wider organisational culture field, ethnography may be considered as a starting point to exploring the complexities of culture, require further examination from a multi-methods, quantitative and qualitative approach (Bellot, 2011, p. 35); however, its choice in this study demonstrates the paucity of research and methods that the researchers could draw from, mirroring earlier developments of organisational culture research in corporate companies.

In Bigby, Knox, et al.'s analysis (2012), culture was conceived within five domains, each existing on a scale in which individual services could be located. They are: (1) *alignment of power holder values*; (2) *regard for residents*; (3) *perceived purpose*; (4) *working practices*; and, (5) *orientation to change and new ideas* (p.458). Taking 'regard for residents' as an example, at one end of the scale is a culture which emphasises difference between staff and those they support, leading to practices of 'othering', while at the other end is one in which staff value the interests, characters and lives of those they support, meaning they act to facilitate activities and aspirations. In the service under investigation, the cultural regard for residents was found to share similarities to cultures previously researched in institutions, with staff understanding those they supported as 'not like us' (p.457). However, improved changes from

institutional culture were seen across other dimensions, such as a willingness to facilitate activities in and out of the houses, and less restrictive and harsh staff practices (p.464). As the domains are interactive, the researchers believed targeted improvement of one may bring about change in others.

The value of the scalable categories put forward by Bigby, Knox, et al. (2012) is that they do not just identify if a service culture is good or bad at *x or y*, but they can be placed in specific relation to other services cultures in order to identify practical disparities in both formal and informal domains. Bigby, alongside various others (Beadle-Brown, Bigby, & Bould, 2015; Bigby & Beadle-Brown, 2016; Bigby, Bould, & Beadle-Brown, 2017; Bigby, Cooper, et al., 2012; Bigby, Knox, Beadle-Brown, et al., 2014), has therefore continued this work, turning the focus towards two services considered to be performing better in an effort to understand ways of developing positive service culture. In one study (Bigby & Beadle-Brown, 2016) methodologically comparable to Bigby, Knox, et al. (2012) though using the five cultural domains to guide data analysis, the researchers found practice and behaviour contrasted with those found in Bigby, Knox, et al. (2012), placing the service culture towards the positive end of the scale across all domains. For example, the staff described those they supported as 'just like us' (p.321), showing a regard contrary to that found in the poorer performing service. Similarly, the service staff differed on their work priorities, with those at the better performing service prioritising engagement with the house inhabitants over other aspects of work (p.324), while those at the other service valued tasks such as cooking or cleaning (Bigby, Knox, et al., 2012, p. 459). The shared conclusions of the Bigby studies (Beadle-Brown et al., 2015; Bigby & Beadle-Brown, 2016; Bigby et al., 2017; Bigby, Cooper, et al., 2012) is that services culture consist of complex interactions between aspects of the formal and informal and this leads to differing types of environments: social, physical and working. If a service understands and guides these interactions, the resulting organisational culture is shown to lead to an increased quality of life for those it supports (Bigby, Knox, Beadle-Brown, & Bould, 2014).

2.4 Service culture in service research

Although the studies of Bigby et al. (Beadle-Brown et al., 2015; Bigby & Beadle-Brown, 2016; Bigby et al., 2017; Bigby, Cooper, et al., 2012; Bigby, Knox, Beadle-Brown, et al., 2014) highlight the importance of service culture in improving the lives of people with learning disabilities, there is a suggestion by Bigby and Beadle-Brown (2016, p. 292) that the importance of its relationship with individual aspects of service provision is disregarded in much research. To refer back to the aforementioned study by Charnley et al. (2019) as an example - this found that a support worker team facilitated group activities for those they supported despite recognising the formal requirement of personalisation, yet the researchers make no

reference to organisational culture or the apparent disparity between the informal and formal cultures at the service. The participating support workers showed a reluctance to facilitate individualised leisure activities by communicating that it was out of their control, requiring outside input such as higher levels of service funding (p.554). This is notably similar to the sentiment of support workers from the underperforming service in Bigby, Knox, et al. (2012, p. 461) who state that ‘the people who write the cheques need to have a look’. The subsequent conclusion of Charnley et al. (2019) is that social care policy would benefit from a ‘capability approach’ (see Sen, 2005), as it could help support workers to recognise and promote the agency of people with learning disabilities. This conclusion suggests that support workers will respond to aspects of formal culture, such as training from a capability approach (Sen, 2005). However, the study (Charnley et al., 2019) findings highlight a staff team that has found two issues with formal culture, first in the form of personalisation, as they value group activities as opposed to individualised modes of support, and second, in the way that funding is provided. In such circumstances, changing policy may have little effect on the outlooks and actions of support workers if the policy is unable to address broader problems of inharmonious service cultures.

A prevalent trend in autism and learning disability service research is to examine the implementation of interventions (see Pellicano, Dinsmore, & Charman, 2014). The intervention most widespread in UK services is Positive Behaviour Support (PBS) (Davison, McGill, Baker, & Allen, 2015) due to the suggestion that it can improve the behaviour and, subsequently, quality of life of autistic people and people with learning disabilities (Allen, James, Evans, Hawkins, & Jenkins, 2005). In a large scale, randomised control trial that included 23 participating services across urban and semi-rural areas in England, Hassiotis et al. (2018) assessed PBS in one of its two primary aims – the reduction of behaviour labelled as challenging – finding no difference between services that implemented it to those that did not. In contrast, Bowring, Totsika, Hastings, and Toogood (2020) found PBS successful in this regard, as well as achieving its second aim – to improve quality of life – when assessed in a community PBS team delivering training to support workers at home and respite services in Jersey. It is unclear why Bowring et al. (2020) conducted the study in this location, though there appear to be notable benefits in service provision in Jersey when compared to those reported in Hassiotis et al. (2018, p. 166), such as minimal post-referral periods (p.201), suggesting disparities between the formal cultures of involved services. As positive service culture has been shown to improve the quality of life of service people (Bigby, Knox, Beadle-Brown, et al., 2014), implementing an intervention in such a service is likely to yield positive results regardless of whether the intervention is effective or not. The opposite may be true in services with poor organisational culture due to the disjuncture between formal (intervention training) and informal (staff actions) cultures.

Contrary to this argument, Paynter and Keen (2015) claim to have found no relationship between organisational culture and the use of interventions at a community based children's autism service, instead finding that support workers 'use the strategies they are most familiar with' (p.1622), rather than adhering to the organisation's guidance on interventions, and subsequently argue that they would benefit from greater degrees of intervention training. However, this is a misinterpretation of service culture: the research is in fact examining the relationship between formal culture – the organisation's perspective on interventions – and informal culture – how support workers implement interventions. This is highlighted by the cultural assessment tool utilised (Russell et al., 2010) which was designed to assess how the formal culture of physiotherapy services impacts the evidence based practice of physiotherapists. In contrast to what Paynter and Keen (2015) conclude, their results suggest that disparities between informal and formal cultures leads to support workers behaving differently to what is formally asked of them. The misinterpretation of service culture by Paynter and Keen (2015), and the omission of it by Bowring et al. (2020) and Hassiotis et al. (2018), creates questions as to whether cost intensive interventions (Davison et al., 2015) have any benefit over the development of positive support worker culture.

An advocate for the implementation of interventions within autism and learning disability services is Ntinis (2019), though here the claim is that PBS in and of itself improves service culture as reductions in behaviour labelled as challenging leads to safer work environments and improved staff morale. The approach taken by Ntinis (2019) is theoretical, drawing from work on consumer culture to suggest that support workers may perceive too high of a cost in delivering interventions due to the related stress and work load; that is, it is easier to carry on as usual. This perception can be counteracted if managers demonstrate the efficacy of PBS to support workers, Ntinis argues, referring to behavioural consumer research (Pennypacker, 1986) that shows 'if potentially resistant consumers realise that behavioural technology is incrementally reinforcing and produces demonstrably greater benefit to them than its competitor (non-intervention in this case), then they will select it' (p.103). In other words, if support workers see PBS to be beneficial over current practice, they will adopt it themselves. Ntinis is suggesting that managers have the ability to reduce support workers' resistance to change by themselves demonstrating what they want support workers to do; in effect, personally aligning formal culture with informal culture. Ntinis (2019) does not refer to any empirical evidence to support this, instead providing an imagined case study to show how this scenario may play out; there is also no discussion on the potential advantages or disadvantages of PBS, as briefly explored in the previous paragraph. The argument is therefore, subject to clear bias. What is significant though is the lack of consideration for how other domains of service culture may impact on support workers' willingness to implement interventions.

Beadle-Brown and Bradshaw (2019) drew attention to this in a response to Ntinas (2019), highlighting for example that support workers will only prioritise the well-being of those they support if they first hold them in positive regard (p.110). Interventions are subject to those that implement them, and thus if a service culture establishes that they do not work 'well enough' to be considered valid, and therefore to be taught to new members as the correct way to perceive, think and feel in relation to those problems...' (Schein, 1985, p. 2), they will serve little purpose.

A meta-analysis of research examining the effectiveness of staff-training in learning disability and autism services (van Oorsouw, Embregts, Bosman, & Jahoda, 2009) suggests that interventions that target improvements in systemic factors, such as staff culture, are beneficial in comparison to targeting behaviours in service people, such as PBS. Drawing from this, James, Hall, Phillipson, McCrossan, and Falck (2013), and in a related publication, Hall, Finch, Kolehmainen, and James (2016), trialled a video-based intervention that targets support workers, as opposed to those they support, in an attempt to create a person-centred culture in a service that provides support to autistic children and adults in an educational and home context (at times, they also refer to learning disability though they do not make clear its particular relevance in this context). The intervention involved a practitioner recording interactions between four support workers and those they support, lasting between 15-20 minutes, before they both then reflectively analysed and discussed the recordings, highlighting positive aspects to encourage confidence, pride and self-esteem in the perception of the support worker role. Participant feedback was garnered in semi-structured interviews, relaying improvements in relationships between them and those they support, greater job-satisfaction and a willingness for colleagues to participate; the researchers concluded that their 'perspectives had been transformed'. Although the authors do not reference formal and informal culture, these findings make a promising suggestion that targeting aspects of informal culture can have a positive effect on wider service culture. However, there is no assessment or analysis of the service culture prior to the research, so it is not possible to assess whether the intervention is improving a poor informal culture or reinforcing one that is positive. Similarly, it is unclear how aspects of formal service culture, such as staffing or previous training, may have affected the results. As the research aims to transform service culture, it is concerning to note the absence of any definition of what service culture *is*, supporting the argument of Bellot (2011, p. 29) that the term is 'fraught with inconsistencies'.

The aforementioned cultural domains framework developed by Bigby, Knox, et al. (2012) provides clarity to what organisational culture is within autism and learning disability services, yet as the above analysis suggests, it is underused within research, even when studies are designed to evaluate service culture. There are for example, no studies that examine day service culture within the UK according to

this framework. The time intensive, ethnographic approach adopted by Bigby, Knox, et al. (2012) may dissuade researchers from investigating culture in this multi-faceted way, though Humphreys et al. (2019) recently drew from the five domains of service culture to develop a quantitative assessment tool that could enable more efficient investigation. Therefore, similarly to the historical trajectory of corporate culture research (see Bellot, 2011), service culture may gain prominence through the use of mixed-methods research in the near future.

2.5 The contribution of service people to service culture

The cultural perspective captured by Bigby et al. (Bigby & Beadle-Brown, 2016; Bigby et al., 2017; Bigby, Cooper, et al., 2012; Bigby, Knox, et al., 2012) is broad and complex, covering both informal and formal aspects of service culture, however, it does so without taking into account the cultural contributions of service people. This is argued against by the researchers who state ‘we acknowledge that the direct voices of the residents are not included; but...’ they ‘are not, however, absent from our data, as our observational methods have captured their behaviors and responses to life in their group homes’ (Bigby & Beadle-Brown, 2016, p. 319 similarly; Bigby, Knox, et al., 2012, p. 453). These comments suggest that the ethnographic methodology, involving lengthy periods of participatory observation with service people at their homes, is constitutive of an approach that includes their perspectives as their day-to-day actions, pursuits, relationships and so on, are included in data collection. However, the cultural domains identified from this approach (Bigby, Knox, et al., 2012) relate only to the actions and perspectives of support workers, with no suggestion of the roles of service people or the manner in which they shape, or wish to shape, service culture. For example, ‘alignment of power holder values’ refers to the relationship between the values of support workers and the organisation, and does not reference the values of service people. In this regard, service cultures could be seen as positive if support workers act in accordance with the values and instruction of formal culture, though this may not correspond to the perspectives and outlooks of service people.

A key principle of organisational culture is that it is ‘socially constructed, the product of groups not individuals, and based on shared experiences’ (Bellot, 2011, p. 30). To contribute requires membership to the related group and so it could be deduced from the cultural domains of Bigby, Knox, et al. (2012) that services consist of two separate groups – one of service people, another of service staff and formal authorities (e.g. managers, researchers or policy makers) – or that service people are independent of each other, experiencing the effects of service staff and formal culture though with no culture of their own. The latter option could be deemed false as research into the experiences of people

with learning disabilities within institutions (Marshall & Tilley, 2013; Stefánsdóttir & Traustadóttir, 2015) – where cultures exacerbated practices of exclusion and segregation in comparison to contemporary services – shows community cultures existed for service people. The former option of two disparate cultures suggests service staff and service people do not share experiences and therefore service staff and formal authorities develop cultures separate to that of service people. On the one hand, it is conceivable that service organisations exist independently of those they support, developing guiding practices and structures that affect the day-to-day actions of those people they employ. On the other hand though, and considering the complexities of service culture that Bigby, Knox, et al. (2012) detail, with interactions between different domains having wider effects on service culture as a whole, it is also conceivable that service people can and do contribute to aspects of culture that, as the earlier definition of organisational culture describes (Schein, 1985, p. 2), determine a service's 'behavior patterns and the visible artifacts such as architecture, office layout, dress codes, and so on'.

A key issue in approaching service culture as consisting of two separate cultures is that to change organisational culture requires one to be a member – it is owned by the group (Bellot, 2011) – thus research developed to improve service culture using the aforementioned cultural domains (Bigby, Knox, et al., 2012) may fail to include the contributions of service people. This is exemplified by the service culture assessment tool developed in relation to these domains (Humphreys et al., 2019), it being a questionnaire that service staff complete. This subordinates service people to others involved in formal and informal service culture: support workers, management, researchers, policy makers and so on. It is contrary to a key tenet of personalisation: 'the means by which people who access care services, whether statutory or self-funded and in all care settings, can shape them to suit their personal needs' (Morgan, 2010, p. 14). In essence, if service cultures are owned by service organisations, personalisation denotes that service people should be able to contribute to their developments.

The topic of leisure can help to highlight how service culture may be conceived to include the perspectives of service people. Through the scope of a study that looked at differences in leisure activities between teenagers with and without cerebral palsy, Aitchison (2003) writes about leisure and disability, pointing to a culture of low expectation that has developed for disabled people. This refers to the way in which disabled people's shared experience of schools, services and support has led to different concepts of leisure to that of non-disabled peers. This includes factors such as who it is done with – family relations, support workers or solo for disabled people, friends for non-disabled; the time it is done – 'free time' for non-disabled people, time dependent on others for disabled people; and, where it is done - accessible or non-accessible spaces. Salient to the study participants was the view that leisure was not primarily about

activities due to their frequent inaccessibility, but instead an opportunity to socialise, suggesting that the shared experience of marginalisation had led to an adaption of leisure culture that prioritised social interaction.

In the context of day services, service people share experiences based on the organisation of a service - its spatial dynamics, the people it employs, the activities available and so on – and in doing so, they shape and define their culture accordingly. Perhaps, for instance, a social culture forms around the use of laptops due to their lack of availability. As service people come and go, culture develops according to the shared ways of coping with day-to-day issues. This inevitably interacts with informal culture as support workers act and respond in relation to their shared assumptions and values, and this, as discussed, interacts with formal service culture. What may also be true is that support workers and service people have shared ways of coping with day-to-day circumstances, that the structure of social care and its formal culture situates them in a shared position – a group – that has its own culture. In relation to leisure activities, for example, support workers and service people may adopt a similar perspective to participants interviewed by Aitchison (2003), in that they prioritise social interaction over the activity itself, and this may be contrary to a formal culture that advocates for skills development or exercise. Despite the apparent disjuncture between informal and formal culture in this example, there may be benefits to both the service person and the support worker.

Evidence of the ways that service people contribute to service culture is presented by Black et al. (2018) in an ethnographic exploration of an adult day service in America, named Holy Family. This service is managed by a local religious organisation and provides support to ageing people with dementia and Down Syndrome. The researchers make an initial assumption that ‘a culture exists in the ADS (adult day service) prior to clients’ attendance. It is replete with (a) social thought about age, aging, and dementia, (b) a model of the aging person and, (c) the social construction of aging and dementia’ (p.730). However, they move past the notion that this culture remains separate from service people by conceptualising the day service as a semiosphere. A semiosphere refers to a concrete and/or metaphorical space defined by the interaction of language and symbols that, as such, can be demarcated by cultural and social values, but that can also hold cultural and social values (Nöth, 2015). For example, day service spaces are defined by their surrounding cultural contexts, such as that of social care funding, personalisation and concepts of disability, though these spaces can also hold their own cultures developed through the interaction of language and symbols of their related people. In viewing day services as semiospheres, Black et al. (2018) position service people alongside support workers, managers, social care professionals and so on, as constructors of day service cultures. To examine this at Holy Family, the researchers used observations of

and interviews with service people and their family relations, support workers and managers, as well as collecting relevant service documents, such as minutes of team meetings. Contributions to service culture were found to be multi-faceted: in relation to formal domains for example, the service used a functional model of competence to assess what each service person could do, and this led to a hierarchical social culture that valued those with greater degrees of participation in activities (p.732). Adding to this, the support workers often imposed a child-like identity on service people, referring to them as if teaching at a school (p.735). Important though were the ways in which service people also shaped culture, for example space was organised by service people so that tables were designated for particular groups – ignoring the assertion of support workers that anyone could sit anywhere and leading to the inclusion or exclusion of new members. Elsewhere, a service person had assumed a role of caring for a doll that prompted the support worker team to develop new methods of practice and communication when discussing the service people's pasts. And of particular prominence was the construction of a music and dance culture that was exemplified on occasions in which the majority of service people sang, danced and applauded each other in shared performances.

The findings of Black et al. (2018) demonstrates ways in which service people construct culture that echoes and contrasts the wider service cultures that they are part of. This is similar to the relationship between informal and formal cultures, though it suggests that these concepts obscure the contributions of service people and may therefore not capture the full complexity of service culture. The service people at Holy Family constructed culture through their everyday lives, both as a group exclusive of the support worker team, as well as a group that included them, leading to patterns of activity, thought and behaviour that are inherent to any organisational culture (Schein, 1985). While the research of Black et al. (2018) is on a small scale, it indicates that the cultural domains put forward by Bigby, Knox, et al. (2012) may themselves interact with elements of service person culture, resulting in new domains that are yet to be conceptualised. That being said, it may be that Bigby et al. (Bigby & Beadle-Brown, 2016; Bigby et al., 2017; Bigby, Cooper, et al., 2012; Bigby, Knox, et al., 2012) never intended to view service culture in this way, and that their research aims only to establish how formal and informal (informal being distinctly related to staff) cultures arise and exist in services, and how this may affect service people's quality of life. Although this approach may be valuable, it does not account for how formal and informal culture may promote positive aspects of service person culture, or how service person and informal cultures interact. Furthermore, to analyse the effect of service culture on quality of life, without taking into account service person culture, disregards the ways in which service people may benefit from the cultures that they create. It views their quality of life as a product of formal and informal cultures, and not as relating to the

communities and cultures that they are part of. If personalisation is to be achieved and service people can shape services 'to suit their personal needs' (Morgan, 2010, p. 14), there must be a recognition of how this is and can be done, and this includes the types of cultures they may wish to cultivate.

2.6 Summary

This literature review was conducted to address the first objective of this research: to examine current understandings of day service culture in relation to the lives of autistic people with profound learning disabilities. The literature shows service culture to be a topic that is primarily considered on a partial basis, through the scope of one cultural aspect or another, with only the aforementioned works by Christine Bigby (Bigby & Beadle-Brown, 2016; Bigby et al., 2017; Bigby, Cooper, et al., 2012; Bigby, Knox, et al., 2012) and colleagues having broached its complexities more broadly, in the context of services that provide support within people's homes. Service culture is shown to have significance as it holds the values and customs that guide the actions, choices and perspectives of service staff and this has an inevitable effect on the experiences of service people. Despite its importance, there is no research that has comprehensively examined service culture within day services for autistic people or people with learning disabilities. The people that contribute to, own and are guided by day service culture can be considered within three key, interrelating groups: service people, support workers and formal authorities (e.g. managers, policy makers, researchers, and health and social care professionals). The contributions of the latter two groups (support workers and formal authorities) are, in various ways, represented in research, though it is not understood how service people may shape, define and experience the cultures that they are part of. The research of Black et al. (2018) suggests that this takes place in the everyday, as this is where service people have the opportunity to 'invent, discover or develop' (Schein, 1985, p. 2) the rules and customs that guide those they share the space with.

Similar to how Bigby, Knox, et al. (2012) recognised that service culture research required new approaches that were sensitive to the specific circumstances of service organisations, so too is there a need for the development of methodologies and tools that are able to investigate service culture in ways that are inclusive of service people. This is a clear gap in the literature, though as there has been no research that has examined service culture within the context of autism and profound learning disability, the methodological implications of carrying out such a study require investigation. One important finding from this literature review comes from the research of Black et al. (2018): that is, to view day service cultures as semiospheres positions autistic people with profound learning disabilities as contributors, as they are necessarily understood as part of the interaction of language and symbols that define culture. A

consequence of this view of service culture is that to explore the roles and practices of autistic people with profound learning disabilities, one must focus on the site of the everyday, as this is where such contributions and interactions take place. Thus moving forward, the following chapters will be dedicated to addressing the second aim of this thesis: to develop a methodological approach to explore the everyday through the experiences and perspectives of autistic people with profound learning disabilities.

Chapter Three

Literature Review: Defining Autism and Severe/Profound Learning Disability

This chapter makes an initial step towards addressing a key aim of this thesis: to develop a methodology for exploring the everyday experiences and perspectives of autistic people with profound learning disabilities. It has a simple premise: to make clear what is being referred to when using the term ‘autism and profound learning disability’, so that the methodological developments, and subsequent research, are grounded in a clear epistemic foundation in relation to who the related population are. To do this, a literature review was conducted to explore the terms ‘autism’, ‘severe learning disability’ and ‘profound learning disability’. This begins with a brief outline of the terms in the context of current academic practice and provides reasoning for conducting the review. Subsequently, the meanings of the terms autism and severe/profound learning disability are explored through literature concerning the two dominant models of disability – the social and medical.

3.1 An issue in developing a methodology with the term ‘autism and profound learning disability’

The following literature review is in response to the analysis of service culture literature and the apparent gap relating to the perspectives and contributions of service people. It is acknowledged that the ethnographic approach adopted by Bigby et al. (Bigby & Beadle-Brown, 2016, p. 319; Bigby & Frawley, 2010; Bigby, Knox, et al., 2012, p. 453) sought to include this, involving spending extended periods of time with service people and collecting relevant data, though the findings primarily focus on the roles of staff within service culture. A reflective discussion is provided by Bigby and Frawley (2010): it explores the practicalities of conducting the project, specifically its inclusive framework and an action research element that involved employing a person with learning disabilities as a co-researcher, aimed at shaping study developments in ways that were relevant to this person’s experiences and views of services. Challenges are outlined, describing how they had not fully anticipated the planning required to involve a person who was unaccustomed to academic practices, though finding it a valuable and beneficial experience for both themselves and the co-researcher. The reflections of Bigby and Frawley (2010) demonstrate how the theoretical and methodological starting points of research can have unforeseen consequences when realised in the practicalities of conducting research. Similar perspectives have been communicated by researchers within both the learning disability (Callus, 2019; Rix, Garcia-Carrizosa, Hayhoe, Seale, & Sheehy, 2020) and autism fields (MacLeod, Lewis, & Robertson, 2014), and so it is important to consider and reflect on the implications of research design and practice prior to, during and after it is conducted.

In the context of autism and profound learning disability, research has largely developed without consideration for the communicative styles and knowledge capacities of related people, so consequently there is a need to explore how methodologies, approaches and methods may impact the process of including, representing and disseminating participants' perspectives (Mietola et al., 2017, p. 264; Simmons & Watson, 2014b, p. 148). Fundamental to addressing this is defining exactly who it is that the researcher seeks to include – who are 'autistic people with profound learning disabilities'? - So that one can make an argument as to why a method or approach is suitable for the circumstances and values of these particular persons. This is an epistemic issue relating to a researcher's knowledge of their intended participants as this will necessarily guide the choices they make in the earliest stages of research – its design, focus, aims and so on.

In a paper that explores the epistemology of learning disability, Goodley (2001) quotes Kincheloe and McLaren (1998, p. 265), stating 'Critical researchers enter into an investigation with their assumptions on the table, so no one is confused concerning the epistemological and political baggage they bring with them to the research site'. However, to make clear one's assumptions in regards to autism and/or learning disability presents an epistemic conundrum due to the multiple claims and perspectives related to each term (Cluley et al., 2020). At times, they are described under one banner, such as 'developmental disabilities' or 'autism with learning disabilities', at others they are kept distinct, in the use of terms such as 'severe autism' or 'learning disability with complex needs'. As Simmons and Watson (2014b, p. 3) point out, even within more defined categories, such as profound and multiple learning disabilities, terminology is manifold and inconsistent within research, policy and practice. It is worth noting the separate academic fields of 'autism' and 'learning disability', meaning that researchers may only consider the implications of working with participants considered to be autistic, or considered to be learning disabled. For example, inclusive practice has been conceptualised in specific regards to autism (Chown et al., 2017; Fletcher-Watson et al., 2019) and to learning disability (Nind & Vinha, 2014; Seale et al., 2015; Walmsley & Johnson, 2003), and so adopting one perspective or another has implications as to how to design and conduct research, though it is unclear as to what is appropriate when both 'autism' and 'learning disability' are relevant to a study.

The following section will therefore examine the literature on the terms of 'autism' and 'profound learning disability' in order to establish an epistemic foundation for which to develop research for persons considered 'autistic and with profound learning disabilities'. To frame this, their meanings will be explored through the scope of the two dominant models of disability – the medical and the social.

3.2 The medical model and its categorisations of autism and learning disability

The medical model of disability views people in relation to their physical health, perceived impairments and cognitive capacities (Officer & Groce, 2009). It is the predominant disability paradigm that influences policy, research, practice and culture: in essence, how disability is known (Fatoye, Betts, Odeyemi, Fatoye, & Odeyemi, 2018). From the perspective of the medical model, disability is conceptualised as a problem that exists inside the person and therefore until medical intervention can assist, they remain disabled. This is a positivist position that situates the disabled person outside a notion of normality – that is, non-disabled - granting access through attainment of measures of physical, intellectual and social functioning (Shyman, 2016).

The American Psychiatric Association (APA) is the foremost authority in defining autism and learning disability according to the medical model, distributing their perspective through the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013). Their aim is to give ‘the best available description of how mental disorders are expressed and can be recognised’ (p.xli), identifying characteristics and attributes of known conditions by drawing together evidence from scientific findings and clinical experience. It is these parameters that guide researchers working from the medical perspective, including how they develop study aims and measures, diagnostic tools and methodologies. In this context, both autism and learning disability are considered cognitive impairments, with the former resulting in symptoms of social and communication deficits and restricted/repetitive behaviours (Volkmar, Reichow, Westphal, & Mandell, 2014), while the latter hinders a person’s ability to process information and their capacity to live independently (Gates, Fearn, & Welch, 2015, p. 10). Their etiological foundations are said to relate to environmental factors and genetic abnormalities, though autism has been found to correspond to hundreds of genes with no specific patterns (Verhoeff, 2015, p. 168; Waterhouse, 2013) and, while some particular learning disabilities may have been tied to a specific genetic basis, such as Down Syndrome (Roizen & Patterson, 2003), the aetiology of learning disability remains unknown in 30-50% of cases (Vahabzadeh, Delaffon, Abbas, & Biswas, 2010). Furthermore, in many cases, genes linked with learning disability are also associated with autism (Thurm, Farmer, Salzman, Lord, & Bishop, 2019; Zhu, Need, Petrovski, & Goldstein, 2014), and it remains unknown as to how specific genetic dispositions correspond to cognitive functioning (Büttner & Hasselhorn, 2011, p. 79).

Recognising that autism and learning disability definitions are broad and have come to relate to diverse populations, the DMS-5 distinguishes categories within each that relate to a concept of how severely the condition disables a person. Traditionally, learning disability categories related to scores of

intellectual functioning, or IQ, they are: mild (IQ 50-70), moderate (IQ 35-49), severe (IQ 20-34) and profound (IQ 20 or below) (Lowth, 2016). Although impaired IQ (below 70) remains a key feature in recognising learning disability according to the DSM-5 – with diagnostic processes involving assessments to situate a person in the above categories (Murray & McKenzie, 2014) - it is acknowledged (DSM-5, p. 33) that scores below this marker are unreliable. For example, a commonly used assessment tool is reported as accurate only ‘to within 18 points above the measured IQ and 28 points below’ (Whitaker, 2010, p. 517), meaning that an assessment of a severe learning disability through IQ measures may be erroneous to the point that the person could in fact be situated within any of the other three categories. Recognising the problematic nature of IQ, the DSM-5 instead adopts adaptive functioning – a description of the level of support a person may require – to differentiate the four categories of learning disability. Each is described in relation to three domains (p.34-36): conceptual - how a person understands information, social – how a person communicates and engages with others, and practical – how a person copes with everyday demands. During diagnosis, these are considered in conjunction through use of a quantifiable assessment tool, such as the Vineland Adaptive Behaviour Scales (Sparrow, Cicchetti, & Saulnier, 2016). Such an assessment relays information in a similar format to that of IQ tests, so for example a result of profound learning disability in relation to the conceptual domain would be 20 or below, with this score across domains resulting in an according diagnosis. A clear issue is apparent if trying to discern the difference between a score of 19 or 21, which would correspond to different diagnoses; also, as Weitlauf, Gotham, Vehorn, and Warren (2014) highlight, these tests are parent-based interviews which have inherent bias due to the nature of parenting and how they perceive their children’s skills and needs. Further empirical issues are presented by van Ool et al. (2019) who found significant differences in scores across domains when using the Vineland Scales to assess learning disability in people with epilepsy, with the most consistent difference being a far lower score in the social domain. This was evident in people across all learning disability categories, demonstrating that the consolidation of scores may indicate a diagnostic label but that the person’s skills and competencies can far exceed it in certain areas. The authors comment that the lower social scores may be due to the close link between autism, learning disability and epilepsy (p.45), though they did not assess whether the participants may be considered autistic prior to the research, so it is not possible to differentiate between participants who scored consistently and inconsistently across the domains. What this highlights though is that the categories of learning disability may be difficult to distinguish and that this is further complicated when considering the possibility of autism.

Turning to autism, adaptive functioning descriptions are used within the DSM-5 to differentiate categories (p.52) - level 1 'requiring support', level 2 'requiring substantial support', and level 3 'requiring very substantial support' – with each level explained through the scope of social communication and restricted, repetitive behaviours. There are similarities between adaptive functioning descriptions presented in relation to autism to those presented in relation to learning disability, for example level 3 autism denotes 'severe deficits in verbal and nonverbal social communication skills', while profound learning disability means 'the individual has very little understanding of symbolic communication in speech or gestures'. The similarity is acknowledged in the DSM-5 (p.58) – 'intellectual disability without autism spectrum disorder may be difficult to differentiate from autistic spectrum disorder...' – not only referencing shared characteristics in communication, but also to the common presence of repetitive behaviours. The only suggested marker of a person being autistic with a learning disability, as opposed to non-autistic with a learning disability, is a greater developmental delay in social communication skills (p.51 and p.58), yet this is also described as a pivotal indicator of learning disability, particularly in regards to severe and profound classifications. Thus according to the DSM-5, while there may be some describable differences in autism and learning disability when people are considered to have higher adaptive functioning, there is little to differentiate them when a person is considered to require a substantial amount of support, meaning such people could be diagnosed as with a severe/profound learning disability, autistic with a learning disability or autistic without a learning disability.

Where there are stronger grounds to differentiate categories of learning disability are between what is termed 'profound and multiple learning disabilities' (PMLD), and severe learning disabilities. PMLD refers to people whose learning disabilities are considered to affect them to the greatest extent, and who also commonly have other health conditions and disabilities, which may or may not include autism. The cognitive ability of people with PMLD is at a developmental level below 2 years, argues Ware (2003), who also employs descriptors such as pre-contingency aware (a lack of understanding of cause and effect), pre-intentional (they do not intend to communicate meaning) (Ware, 2004) and pre-volitional (without agency) (see also Mercieca, 2013). These descriptors are however, just that: terms that are variably used to describe the perceived developmental level of people with PMLD, as opposed to specific and measurable indicators of what it is to be a person within this group. For example, Chadwick, Buell, and Goldbart (2019) surveyed speech and language therapists to examine how communication was assessed in people with PMLD, finding that they were more interested in learning how to best communicate and engage with a person, than compared to establishing their communicative developmental markers. The authors also reported that assessments involved 'an eclectic mix of published, unpublished and self-

devised assessments' (p.345), suggesting, as respondents did themselves (p.346), that perception and experience, rather than robust evidence, underpins the ways that people come to be defined within the category of PMLD.

People with PMLD are said to have 'more than one disability, the most significant of which is a profound learning disability' (PMLD Network, 2017) (p.12), though as previously mentioned, what marks a profound learning disability is levels of adaptive functioning, which is also how autism is defined. By this token, it is unclear what marks a person with autism 'level 3' and additional disabilities, as different to a person with a profound learning disability and additional disabilities. The boundaries between PMLD, profound learning disability, severe learning disability and autism 'level 3' are vague, as none of them have any form of reliable assessment or measurement. So, while a person with PMLD may be understood to have the highest support need and the greatest cognitive impairment, it is difficult to distinguish at what point these needs and impairments become severe learning disabilities, or how they are different to autism with profound learning disabilities, or autism level 3. As Nind and Strnadova (2020, p. 1) point out, it is not possible to 'supply a universally agreed definition of profound intellectual and multiple disabilities (as none exists)'.

3.3 Defining and differentiating autism and severe/profound learning disability

The issue of differentiating autism and learning disability in people with complex needs was recently highlighted by Thurm et al. (2019), who conducted a literature review from the perspective of the medical model in order to address this challenge. The authors point to the same issues existing in the DSM-5, namely that distinguishing autism from learning disability on the basis of higher levels of social impairments is problematic when this is also considered inherent in severe and profound learning disability. They begin by pointing to changes in children's diagnostic rates in America over the past 20 years (Fombonne, 2003; Taylor, Jick, & MacLaughlin, 2013), making a suggestion that an increase in diagnoses of autism and a decrease in learning disability indicates a shift in how diagnostic practitioners are recognising disability. Thurm et al. (2019, p. 3) note that severe/profound learning disability, in comparison to mild/moderate learning disability, is more frequently diagnosed alongside autism than as a learning disability alone, indicating that practitioners correlate the two when assessing people with complex needs. Together with the aforementioned similarities in social impairments and restricted/repetitive behaviours, Thurm et al. (2019, p. 5) also recognise the common presence of sensory impairments/differences in relation to the two diagnoses. To overcome these issues of similarity, Thurm

et al. (2019, pp. 6-7) make six suggestions to differentiate the conditions at point of diagnosis – each is addressed sequentially below.

First, the authors recommend that the person's IQ should be taken into account as this will give context to developmental targets, though as discussed earlier, such assessments are unreliable in lower IQ scores and even discouraged in the DSM-5. The authors are suggesting that an autistic person may display behaviours that appear as though they have a learning disability, but that IQ scores could show them to have higher cognitive functioning than expected, and thus autism rather than severe/profound learning disability is present. However, even if IQ measures were reliable, this would not distinguish between a diagnosis of autism and severe/profound learning disability to that of severe/profound learning disability alone. Second, sensory and motor impairments are suggested by the authors to be common in people with profound learning disabilities and therefore should be considered a marker to differentiate the diagnosis from autism, yet sensory impairments/differences are a key indicator of autism (Conn, 2015) while motor impairments may also be apparent – that is, they are not unique to profound learning disability and found in relation to many conditions, including autism (Ming, Brimacombe, & Wagner, 2007). Third, the authors suggest that observing a person's development into late childhood and adolescence may reveal the absence or presence of a severe/profound learning disability, depending on progress in adaptive functioning, though, similarly to the first point, this would fail to differentiate between autism and profound/severe learning disability to that of profound/severe learning disability alone; that is, according to the medical perspective, it would only indicate autism without learning disability, or with mild/moderate learning disability. Fourth, fluctuation of a person's social impairments is said to demonstrate the absence of autism, as the authors believe this to be a key marker that would remain consistent for autistic people while varying for people with learning disabilities depending on their mental health. This however suggests that autistic people with severe/profound learning disabilities have no capacity to progress their social skills, or, if they do, that their mental health has no impact on the ways in which they socialise; this is not the case though, as evidenced in the many accounts of autistic people whose social engagement varies according to their mental health circumstances (see Caldwell, 2017). Fifth, the authors warn that autism assessment tools may be sensitive to extrinsic conditions, such as ataxia or dysarthria, so risk a resulting autism diagnosis when it should be that of severe/profound learning disability and the extrinsic condition. However, the authors do not make it clear as to when it would be appropriate to diagnose autism with severe/profound learning disability and the extrinsic condition - the presence of ataxia or any other condition cannot confirm the absence of autism. The sixth and final suggestion is that diagnostic practitioners should be aware of their own biases when assessing

social impairment, taking into consideration the cultural background of the person, as this may affect the level of impairment perceived. For instance, some cultures may discourage eye contact in social engagement (see Perera & Courtenay, 2017) and this may be considered part of a social impairment by practitioners, indicating an autism diagnosis, when in fact a diagnosis of learning disability would be appropriate. Be that as it may, there is no suggestion as to how to understand whether a characteristic is related to a cultural background or to that of autism; it could in any circumstance be relevant to both.

The primary flaw in the approach of Thurm et al. (2019) is that their focus is on distinguishing autism from severe/profound learning disability, rather than autism with severe/profound learning disability from severe/profound learning disability alone, as it does not address any differences when people have complex needs. This is, as they highlight (p.3), where diagnostic practitioners observe the highest degrees of correlation. An empirical study that aimed to determine such differences was conducted by Hoevenaars-van den Boom, Antonissen, Knoors, and Vervloed (2009), focusing on ten people with deafblindness and severe learning disabilities, five of whom (4 male and 1 female) were considered to be autistic, and five (4 female and 1 male) who 'did not show any signs of autism' (p.551). To assess behavioural difference, video recordings of participants engaging with diagnostic practitioners were analysed by the researchers and two experienced practitioners, one related to autism and the other to learning disability, without knowing which were considered to be autistic and which were not. Significantly lower scores were recorded in 'openness for contact, reciprocity/join attention and communicative signals/functions' (p.554) for those participants considered to be autistic, though non-significant or no difference was reported in categories of 'coping with changes, problem solving strategies, stereotyped behaviour and exploration and play'. The authors subsequently conclude that the categories which demonstrated significant difference could be used to differentiate deafblind people with severe learning disabilities and autism, to those without autism. Issues in this study are manifold though to begin, the recruitment methods are unsound, involving a three person panel (a psychiatrist, psychologist and independent deafblind expert) assessing 95 people with deafblindness and severe learning disabilities as to whether they had autism, not through use of a standardised assessment tool but via their personal judgements. The authors (p.551) argue that a study by Brown, Hobson, Lee, and Stevenson (1997) supports 'a rationale for using an expert judgement on autism instead of assessment instruments', yet this research attempts to discern differences and similarities between blind children with and without autism, providing no evidence or arguments that would support an experts over instruments approach in identifying autism during research recruitment. The problem of the three person panel is evident as they could not decide whether 32 of the 95 potential participants could be considered autistic, meaning that

they failed to meet the eligibility criteria to participate. Consequently, there is a high risk of confirmation bias as the panel has excluded people whose behaviours would have fallen into both autistic and non-autistic categories, raising questions as to how to discern the presence or absence of autism in such people.

The judgements of the three person panel in Hoevenaars-van den Boom et al. (2009) leads to a notable difference between those participants considered autistic and those not – that is, 80% of the autism group were male while 80% of the non-autism group were female. This may be a reflection of the era, since understanding of autism in males and females has developed in the past decade, from the perception that autism generally affects males (see Baron-Cohen et al., 2011) towards the view that it can be characterising differently in females and males, particularly in regards to social engagement (Dworzynski, Ronald, Bolton, & Happé, 2012; Rutherford et al., 2016). For example, Hiller, Young, and Weber (2016) found that social compensatory strategies (e.g. how to respond to social situations that are not fully understood) were different in autistic boys to autistic girls, with the former choosing isolation strategies (leaving or remaining a passive observer), and the latter implementing mimicking skills (copying those they were engaging with or those around them). According to this, the social domains highlighted by Hoevenaars-van den Boom et al. (2009) as being key to differentiating the presence or absence of autism in people with severe learning disabilities – reciprocity/join attention and so on – may in fact be wholly explained by the gender difference of their participants; that is, by today's measures, the differences may be recognised as correlating to the presence of autism in males, and the presence of autism in females. Inadvertently then, the study results may further complicate the issue of discerning differences between autism with severe/profound learning disabilities, and severe/profound learning disabilities alone, as one may be able to tentatively suggest that the distinguishing factor presented in the DSM-5 – level of social ability – may appear differently in relation to gender.

Autism has also been categorised as different to profound learning disability by Bellamy, Croot, Bush, Berry, and Smith (2010), in their attempt to define PMLD. In this study, the authors drew together a range of definitions of PMLD from the PMLD literature, such as those presented by Samuel and Pritchard (2001) and Ware (2003), as well as from PMLD organisations (e.g. PMLD Network), and government issued reports with a focus on learning disability (though not autism) (e.g. DoH, 2009). To assess these definitions, the researchers then used interviews and focus groups to garner the perspectives of care staff from day services for people with PMLD (though not autism), parents of people with PMLD (it was not stated whether they did or did not have an autism diagnosis), and a range of health care professionals (it did not state whether they had expertise in autism). A response from the care staff participants stands out:

though they preferred a definition of PMLD by Lacey (1998) which stated that ‘autism can be difficult to establish if there’s no communication’ (p.230), they contended that autism was not a core feature of PMLD. Indeed, across all the groups, autism was not considered a defining characteristic of PMLD, and its inclusion was seen as ‘problematic’ (p.230). What the paper does not address though is why the inclusion of autism is problematic, it just *is*. There is no explanation of what participants think autism is, when they think it would be evident in a person with PMLD, or how they could distinguish such matters. The sources which the researchers drew from are almost entirely linked to PMLD or learning disability, as opposed to autism, yet they offer no critical reflection on this. Despite recognising in their earlier descriptions that autism is often present in people with PMLD, the authors conclude with a definition of PMLD that has no reference to autism, only a veiled indication if it (‘may include neurological problems’) (p.233). In essence, the researchers did not distinguish whether autism is part of PMLD, rather they asked a select number of people commonly concerned with PMLD whether they would like autism to be part of PMLD, to which they declined.

In their closing section, Thurm et al. (2019, p. 7) make the same argument put forward here, in the opening paragraphs of this literature review, that it is vital that researchers make clear their assumptions when beginning research into autism and learning disability in relation to people with complex needs, as this affects methodological direction, assessment tools, study aims and so on. However, despite their considered effort, and that of others, to distinguish differences in a variety of ways, it remains clear that it would be inappropriate to use the medical model to claim that autism with severe/profound learning disability is categorically different to severe/profound disabilities alone. Salient is the authors (p.6) advice that the clinical judgement of an experienced practitioner is more reliable than that of any prescribed definition when differentiating the two diagnoses, suggesting that any research developed with such a definition as an epistemic foundation can, at best, only be considered as being nearly as reliable as the perception of a single person. One can establish that when a person has a complex needs, the terms ‘autism’, ‘severe learning disabilities’ and ‘profound learning disabilities’ share a pool of distinguishing characteristics – those outlined in the DSM-5 (American Psychiatric Association, 2013) such as ways of interacting, socialising, understanding and communicating – that fluctuate depending on an individual person and their surrounding environments. When taking into account other factors such as levels of mobility or other impairing factors, there may be small changes in levels or type of support required, though as the definition of ‘complex needs’ describes (see Think Local Act Personal, 2020), this will remain at a high level throughout the lives of related people, and concern ‘many aspects of daily life...’.

The literature review will now move to examining the terms of ‘autism’ and ‘severe/profound learning disability’ from the perspective of the social model, looking to add to the understandings gained from the medical perspective and establish an epistemic foundation with which to develop research for related people.

3.4 Exploring autism and learning disability according to the social model

The social model of disability was first conceptualised by Mike Oliver (1981) who argued that disabled people were disabled by societal barriers, rather than their impairments, and that as a consequence, societal change is required in order to address the inequalities of disability. Disability from this perspective is a social construct (Areheart, 2008), affecting people in relation to the surrounding social context, with those that share commonalities through physiological impairments also sharing experiences of disability. Initially, the perspective of the social model helped to examine and challenge the disabling barriers faced by people with physical and sensory disabilities (e.g. Shearer, 1981), though this perspective began to expand in the 1990s, as the self-advocacy movement amplified the voices of people with learning disabilities (Chappell, Goodley, & Lawthom, 2001; Walmsley & Johnson, 2003, p. 60). More recently, the social model has also gained prominence within autism research (e.g. Arnold, 2010; Waltz, 2006; Woods, 2017), as autistic and non-autistic researchers (e.g. Bertilsdotter Rosqvist et al., 2019; Chown et al., 2017) have sought to challenge and disrupt exclusionary practices and processes that autistic people face.

According to the social model, the biological and cognitive differences of autism are not innately problematic, since given the correct societal responses, such as changes to environments and public attitudes (see Woods, 2017), the experience of disability will dissipate to greater or lesser extents. Autism in this regard can be seen as a way of thinking, being and experiencing – a ‘form of life’ (Chapman, 2019, p. 421) that requires acceptance though, due to its difference to non-autistic forms, currently results in a disabling effect on autistic people. Learning disability as understood from the social model emphasises the autonomy and capability of people labelled as such, highlighting the need for opportunity in a society that has traditionally assumed them to lack capacity (Chappell et al., 2001). It recognises the environmental factors that contribute to the construction of the label, such as exclusionary educational practices, so as to challenge the very notion of impairment (Goodley, 2001). People with learning disabilities are – as the name of the self-advocacy group suggests – People First, and it is their prerogative to construct the label according to their experiences and perspectives.

As disability according to the social model is a ‘disadvantage that stems from a lack of fit between a body and its social environment’ (Goering, 2015, p. 134), the categories presented by the DSM-5 within

autism and learning disability can be seen to relate to the social, cultural and political contexts in which they have developed. Therefore, critical analysis of such themes may provide further insight into how to distinguish and define autism and learning disability in the context of people considered to have a complex needs. Two concepts relevant here are those of 'emic and etic' perspectives (Goode, 1992 & 1994), and that of 'epistemic communities' (O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow, & Orsini, 2016). The former was coined by David Goode (1992 & 1994) through his work researching the lives of children born 'with congenital deaf-blindness and mental retardation' (Goode, 1994, pp. 52-53). This research took place within school and medical environments, with Goode finding those who engaged closely with the children developed an understanding of them that differed from the medical practitioners', whose perspectives were founded on the medical model. This arose from the children demonstrating a social existence involving self-awareness, an engagement with others and a capacity to develop shared, idiosyncratic languages. Goode (1992) theorised these different perspectives as the etic and the emic, the former being that of the clinical outsider, and the latter relating to the empathetic insider; in essence, engaging closely with autistic people with severe/profound learning disabilities changes how a person understands the terms, disrupting the concepts from the inside out.

The concept of epistemic communities originates in the feminist work of Lynn Nelson (1993, 1995) which focused on epistemology – specifically, the nature of evidence and epistemic agency. Epistemic agency relates to the ways in which people form and revise facts (Setiya, 2013) - and the extent to which one intentionally acts in, as opposed to consents to, such processes (Cascio, Weiss, & Racine, 2020, p. 4). Nelson (1993, pp. 121-123) makes a case that knowledge construction is a holistic process, with each supporting piece – that is, evidence, methods, theories and so on – supporting the other pieces. From this perspective, all pieces constitute evidence as they are part of a wider whole that implicates knowledge. So for example, the theoretical underpinnings of disability change from the medical model to the social model, thus requiring different types of evidence and methods to produce knowledge, yet each of these components must be considered as evidence in order to clarify what they are suggesting. Nelson goes on to argue that evidence of any sort is laden with socio-political value – 'what counts as evidence depends on who knows, and who knows is a function of the social context' summarises Calvert-Minor (2011, p. 347). In this regard, epistemic agency is controlled, or at least heavily mediated, by the community in which an individual is situated, deciding what does and does not constitute evidence and guiding further knowledge construction in its mould.

Nelson's epistemological perspective has been drawn from by Whelan (2007) in relation to women with endometriosis, and in turn, by O'Dell et al. (2016) in relation to diagnostic categories,

particularly autism. It is the assertion of O'Dell et al. (2016) that to make sense of diagnostic labels, different social groups draw upon aspects of science and culture that result in particular epistemic communities. The authors highlight (p.173) how different geographical areas have different notions of what autism is and this affects how subsequent knowledge is constructed around the term. This argument is consequently expanded on through Ian Hacking's concept of looping (Hacking, 1995, 2002), as O'Dell et al. (2016) maintain that such knowledge constructions not only affect the definition and categorisation of autism, but also autistic people themselves. An example given is that of Brazil, in which autism, according to the federal government, is understood from a psychiatric perspective as a form of 'mental suffering' and this guides how research is funded and developed (see Rios & Andrada, 2015). This perspective can be understood as that of the etic, though as Rios and Andrada (2015) discuss, the emic perspective is now changing the concept of autism in Brazil, as a community of parents draws from their personal experiences of their autistic children to challenge how the diagnostic label is widely understood. In this instance, the developing definition of autism affects the wider social and political landscape, which in turn affects the lives of autistic people, as schools, services, health care practitioners, and so on, respond to them accordingly.

The theories of epistemic communities and the emic/etic presented here describe how diagnostic labels are constructed and reified in different contexts. To look at this in the context of autism and/or severe/profound learning disability, three key areas were identified by Goodley (2001) in an early critical analysis of severe learning disability that remains relevant today - these are: challenging behaviour, narrative, and personhood. Though this will be further expanded on, Goodley's arguments can be summarised as follows: in regards to challenging behaviour - often linked with autistic and non-autistic people with severe learning disabilities from a medical perspective (see Pilling, Marcus, Whittington, & Murphy, 2015) - Goodley (2001, pp. 213-215) highlights how organisations train social care practitioners to focus on a person's actions as opposed to the effect of surrounding environments, problematising the way a person copes with the demands of everyday, exclusionary spaces. Next, Goodley argues that narrative has been constructed without the perspectives of people with severe learning disabilities, rather their stories have been 'saturated' (p.218) with problems by outside observers and thus so too has the label. And finally, Goodley draws attention to the historical and continuing objectification of people through their diagnostic labels, such as stating a characteristic is because a person is thought to have a learning disability as opposed to it being part of their personality, resulting in the violation of personhoods for those people labelled.

3.5 The construction of personhood, narrative and challenging behaviour in the context of autism and severe/profound learning disability

The issue of personhood raised by Goodley (2001) has been a popular subject for philosophers (DeGrazia, 2005; McMahan, 2002; Singer, 2009) in the context of people they describe as ‘congenitally severely retarded’ (McMahan referenced in Vehmas & Curtis, 2017, p. 508), which according to their descriptions, would relate to severe/profound learning disabilities, with or without autism. This primarily relates to the philosophers’ perceptions of cognitive and social functioning, which they regard people with profound learning disabilities as lacking to the greatest extent, and thus they use people labelled as such as objects of moral assessment, equating their existence to dogs (McMahan, 2002) and other non-human animals (Singer, 2009) and arguing that they are devoid of humanity, personhood and worth (DeGrazia, 2005; McMahan, 2002). Like the medical model, these philosophical views situate learning disability within the person, who in turn is situated on a hierarchy of humanity measured through a perception of cognitive capacity. The philosophers mentioned argue that these are theoretical musings, devoid of moral or political judgement (see Keith & Keith, 2013, pp. 72-74), and therefore require no ‘empirical substantiation’ (McMahan referenced in Vehmas & Curtis, 2017, p. 508). From the epistemological perspective of Nelson (1993) however, these theories *are* evidence, derivative of, and contributing to, the dominant understandings of cognitive capacity and social functioning that exist within society, that which is framed from the medical perspective under autism and severe/profound learning disability. It has existed, as Keith and Keith (2013, pp. 55-60) discuss, as the authoritative line of thought since the ancient Greek philosophers wrote about intelligence.

A counter to DeGrazia’s (2005) argument that personhood is absent in people with profound learning disabilities is provided by Simmons and Watson (2014a) who draw from their empirical, phenomenological study involving Sam, a person labelled as such (Simmons & Watson, 2014b). Personhood for DeGrazia is contingent on a human demonstrating sociality, communicative abilities and self-awareness – all said to be deficient in relation to both profound learning disability and autism from the perspective of the medical model. However, in exploring the experiences of Sam within different school settings, Simmons and Watson (2014b) found DeGrazia’s essential features of personhood to be evident in him through the ways he communicated, acted and interacted, demonstrating the unreliable nature of the label in defining a person and therefore exposing the flawed philosophical arguments. Here, the change in evidence – theoretical (phenomenology) and empirical (observations of and close engagement with the person) – provides a different knowledge of profound learning disability, showing that a person labelled as such may be seen to have varying capabilities and characteristics depending on

the social and physical environments that they are observed in. Sociality was also identified by Kittay (2002, p. 266) as a key aspect of personhood: a person's 'capacity to be in certain relationships with other persons, to sustain contact with other persons... and to have a life that another person can conceive of as an imaginative possibility for him - or herself'. Contrary to DeGrazia's argument though, Kittay (2002) locates evidence similar to that of Simmons and Watson (2014b), finding personhood to be in people with profound learning disabilities, as she knows, from personal experiences with her daughter, that people labelled as such develop and maintain sincere and meaningful relationships. Thus, for both Kittay and Simmons and Watson, enabling the emic perspective provides understanding of people with profound learning disabilities according to the experiences they live and share with others.

Turning to narrative, Goodley (2001) argues that this has been constructed in a way that victimises people with severe learning disabilities as it has been done so from the etic perspective with little understanding of their first hand experiences. Life story work has been a means to challenge this, shifting the focus from understanding people with learning disabilities '...as patients or subjects to considering them as people with their own unique life' (Hewitt, 2000, p. 90) – '...not "what people are" but "who people can be"' (Satchwell & Davidge, 2018, p. 349 referencing Banks, 2007). This approach is embedded in an epistemic research community that values the ways in which people make sense of their lived experience; this is prioritised as evidence as it is seen to construct knowledge that tells us something of the person, from their perspective. In doing so, the theoretical perspective of narrative changes, moving away from traditional conventions of temporal and spatial coherence towards a non-linear model in which lines of narrative develop simultaneously, as sense is made of them (McCormack, 2017, pp. 28-29).

Osteen (2013) for example details the archetypal autism narrative through a critical analysis of books, films, television and newspapers, showing that autistic people are primarily narrated as being disabled, but not too disabled, while hiding savant abilities – super powers – that aid them on their quest for a miraculous cure. This, for Osteen (p.263), is a way for non-autistic people to venture into the 'strange' world of autism, facilitating its inclusion from a safe distance. However, more recent work by Smith (2016) distorts this narrative structure, focusing on the everyday stories of a young autistic person at a dance class, showing how her friends, peers and dance teachers did not know her 'through a lens of autism and childhood' but through the way in which she constructed an embodied self – through dance. From this perspective, knowledge of autism is constructed according to the minutiae of everyday life, changing according to its particular context as the etic perspective creates new understandings. Narrative as such complicates the distinction of autism and severe/profound learning disabilities further, requiring evidence sought from the related communities in the context of their everyday circumstances. A rare example is in

the research of McCormack (2017), who worked with people with profound learning disabilities and their families to learn of their stories, finding these to be embedded in the people, schedules and spaces that they have aligned themselves to over the course of their lives. Knowledge here, in the form of narrative, develops and forms at a measured pace, through the small communities in which people with profound learning disabilities are part of, involving family relations, friends, peers and support staff. Consequently, evidence of what profound learning disability *is* changes accordingly, as they come to know it in relation to their wider biographies.

Behaviour, according to the DSM-5, is pivotal in locating autism and/or severe/profound learning disability in a person and, in regards to social behaviour, is the apparent key difference between autism with severe/profound learning disabilities, to severe/profound learning disabilities alone. What Goodley (2001) draws attention to is the construction of behaviour labelled as challenging, commonly linked with autistic people with severe/profound learning disabilities (Koritsas & Iacono, 2012; Tilley, Ledger, & Bardsley, 2015) and understood as a key factor in their social exclusion (Bigby, 2012, pp. 361 - 362). Service provision is one area where knowledge of challenging behaviour is constructed: for example, a discourse analysis of challenging behaviour referrals at autism and learning disability services (Haydon-Laurelut, Nunkoosing, & Millett, 2014; Nunkoosing & Haydon-Laurelut, 2011) shows how the everyday actions of supported people are understood as challenges from the perspectives of staff – ‘they eat their food too quickly, and they don’t go to the toilet when others decide they need to, their asking questions are verbally abusive’ (2011, p.415). The authors suggest that a fine line exists between seeking support and challenging staff members, with the service organisation attempting to justify its existence by demonstrating the innate risks of the people they support. Service managers utilise the medical perspective, that of the *etic*, viewing the challenge and the diagnostic label as embodying those they support and referring to them as such, ‘this is autism and quite severe challenging behaviour’ (2014, p.295). It is, in relation to Nelson’s (1993) theory, their theoretical evidence, supporting their knowledge of the terms alongside the observed evidence of behaviour.

The challenge that Goodley (2001) aims at the epistemology of learning disability is, as the above points show, still relevant in the contemporary context of autism and severe/profound learning disability. This had been a process to encourage the development of ‘mutually inclusive social theories of disability and impairment that are open and inclusive’, though it remains that the social model and the medical model are the predominant theories with which to understand and frame the terms. The use of the social model as the theoretical evidence helps to deconstruct knowledge as supported from the medical perspective, showing the terms in relation to ongoing social and cultural contexts as opposed to definable

ontological states. It tells us that these labels are constructed within epistemic communities who each have their own governing structures that guide what constitutes evidence. Despite the separate terms of 'autism' and 'severe/profound learning disability' and the apparent potential for divergent and diverse knowledge constructions in the context of people with complex needs, the analysis of personhood, narrative and behaviour shows that such persons have been, and continue to be, defined and known in similar ways. In individual circumstances, the emic perspective can provide personal insights that challenge the categories more broadly, and this only further weakens any distinguishing factors.

3.6 Summary of 'autism and severe/profound learning disability'

In reviewing 'autism' and 'severe/profound learning disability' through the scope of the medical and social models of disability, one can argue that there is no epistemic reason that the terms should remain separate when developing methodologies for people with complex needs. However, as the terms relate to communities of people – the autistic community and the learning disability community – each with their own values, customs, histories and perspectives, there may be ethical issues that arise when compounding the terms, as well as in continuing to view and research them in separate (occasionally intersecting) academic spaces. Can autistic people with complex needs be seen to represent people with severe/profound learning disabilities, and vice versa? And is it appropriate to assume that research practices developed for autistic people with complex needs are ethically appropriate for people with severe/profound learning disabilities, and vice versa? These questions and concerns represent a gap in the literature that require addressing if two objectives of this thesis are to be addressed: first, to establish ethically sensitive ways of developing research for autistic people with profound learning disabilities. Second, to establish ways of researching with autistic people with profound learning disabilities that are sensitive to the values and perspectives of their related communities: that of the autistic community, and people with learning disabilities (Chapter 1.3).

And so, the following chapter will begin by exploring the above concerns so that as a methodology is developed to explore service culture in ways that are inclusive of service people, specifically autistic people with profound learning disabilities, 'no one is confused concerning the' underlying 'epistemological and political baggage' (Goodley (2001) referencing Kincheloe and McLaren (1998, p. 265)).

Chapter Four – Methodology – Part One

An Academic Space of Autism and Profound Learning Disability

Chapter four is presented in two parts which address the second aim and its related objectives detailed at the beginning of this thesis (Chapter 1.3), those relating to the development of a methodological approach for researching the experiences of autistic people with profound learning disabilities. The first of these objectives was to establish ethically sensitive ways of developing such a methodology. As the literature review had highlighted the lack of epistemic justification for separating the terms ‘autism’ and ‘severe/profound learning disabilities’, in relation to people with complex needs, this chapter begins by discussing the related ethical implications. Specifically, it explores the issue of academic and political representation for people that may be considered autistic with severe/profound learning disabilities. The purpose of this discussion is to establish who the methodological approach is being developed for, so that their views, lifestyles and customs can be taken into account when considering how to research their experiences. An argument is made that the separation of the terms exacerbates the marginalised position of people with complex needs, as their perspectives are not represented within broader discourses around autism and learning disability. It is contended that people with complex needs related to the terms ‘autism’, ‘severe learning disabilities’ and ‘profound learning disabilities’, share what Kraus (2015) terms ‘life-conditions’, which relates to the circumstances of their lives. Using this perspective, an academic space of ‘autism and profound learning disability’ is conceived: a space in which methodologies can be developed in relation to the shared life-conditions of related people, with consideration for their perspectives and circumstances. The first part of the chapter concludes with a discussion relating to the second objective of the methodological development: to establish ways of researching in the space of autism and profound learning disability that are sensitive to the views of the related autism and learning disability communities. This is done by drawing from the ‘third space’ of inclusive research, as discussed in relation people with learning disabilities (Seale et al., 2015) and autistic people (Andrews, Hodge, & Redmore, 2019; Bertilsdotter Rosqvist et al., 2019). A recommended method is to research with autistic people with profound learning disabilities by seeking input from their social and support circles, though some ethical considerations are highlighted in relation to the concepts of the double empathy problem (Milton, 2012a) and inclusion phobia (Goodey, 2015).

The second part of this chapter makes a contribution to the space of autism and profound learning disability: a novel methodology to explore related people’s everyday experiences. This methodology is first given an epistemological grounding, with consideration of issues found in relation to the double

empathy problem and inclusion phobia. Subsequently, the third objective relating to the methodological development is addressed by exploring research approaches: specifically, what could be the most appropriate ways to research the experiences of autistic people with profound learning disabilities, with consideration of their communicative approaches and day-to-day circumstances. It is consequently argued that the phenomenological concept of lifeworld fractions (Ashworth, 2016), used within a process of 'thinking phenomenologically while doing phenomenology' (Berndtsson et al., 2007), provides an approach to explicate the experiences of autistic people with profound learning disabilities. The approach does this by identifying aspects of experience significant to participants' lifeworlds, and consequently directing the researcher to relevant methods and theoretical outlooks that can be used to investigate phenomenon from the participants' perspectives. Because the methodology is adaptable to diverse circumstances, prompting the researcher to introduce methods and approaches relevant to participants' outlooks, communication and circumstances, it is contended that it represents an inclusive approach for researching with autistic people with profound learning disabilities. Inclusive in this context relates to the final objective of the methodological development: to enable a practical research process in which autistic people with profound learning disabilities can meaningfully participate, and, where possible, shape it according to their perspectives.

4.1 An issue of representation

The autism and learning disability fields have used the social model to explore disability in ways that they argue are ethically justified for use with the respective populations, seeking input from people that identify/are identified with the terms in order to research in ways that are representative of their perspectives (see for example Bertilsdotter Rosqvist et al., 2019; Chown et al., 2017; Walmsley & Johnson, 2003; Woods, 2017). It is this aim of representation that has caused issue in regards to people with complex needs, as there is has been uncertainty as to how to involve them within research processes (e.g Nind, 2008, p. 16). Furthermore, it is has been acknowledged that the impairments of people with profound learning disabilities cannot be 'explained away' through analysis of the surrounding political and social contexts (Mietola et al., 2017, p. 266). For Cluley et al. (2020, pp. 237-240), this demonstrates that the social model as theoretical evidence does not support an inclusive knowledge of people with learning disabilities and complex needs, as those epistemic communities that have developed with its use (those related to critical and inclusive disability studies) have commonly marginalised those people labelled as such, as opposed to confronting the issue of their evidence. The result of this, Cluley et al. (2020, p. 251) argue, is a research field that is only partially representative of people with learning disabilities, and

subsequently the production of government policy and strategies (e.g. Department of Health, 2001) that 'explicitly exclude' people with complex needs.

To improve opportunities for people with learning disabilities and complex needs to be represented in research and policy, Cluley et al. (2020) propose that the concept of learning disability should be viewed from the perspective of the 'ontological turn' as opposed to the social model of disability. The 'ontological turn' situates the 'learning disabled body' as an assemblage: 'a product of ongoing and ever-changing biological and social interactions (including objects, culture, environment, discourse and economics)' (Cluley et al., 2020, p. 253). Within all such interactions exists interdependent actors, each impacting the 'becoming-bodies' (p.253) of people with learning disabilities. And so practically speaking, for researchers and policy makers that takes such a perspective, Cluley et al. (2020, p. 253) contend that 'the voices of self-advocates and government ministers thereby become equally valid' and thus 'the voices of those who are least heard would have a fighting chance of representation'. This is a bold claim as it is suggesting that it is appropriate for academics and government officials working from the perspective of the social model to dedicate considerable effort to change working practices and processes so to bring attention to 'the heterogeneous continuum of people with learning disabilities' (p.253), though the authors are unsure as to whether it would improve the current representative position of those with complex needs. Furthermore, though Cluley et al. (2020) are highlighting the absence of a population's voice from the government strategies that affect them, there is also an absence of, or reference to, the voice of autistic people within the discussion, and so it is unclear to what extent their argument may also apply to autistic people with complex needs. Adopting the social model has been declared a key factor in the creation of emancipatory autism research by autistic and non-autistic researchers (Bertilsdotter Rosqvist et al., 2019; Chown et al., 2017; Woods, 2017). Therefore, it could be seen as a challenge to the values of the autism community to develop research with autistic people with complex needs that adopts a different perspective of autism to that understood through the social model.

The issue of exclusion and representation within communities formed through shared disability is also explored by McCoy, Liu, Lutz, and Sisti (2020) who focus on autism and a population that is diverse in backgrounds, views and capabilities. Their focus is ethical and political, discussing who it is that should be able to advocate for autistic people 'with severe disabilities' (p.22), namely those who may not be able to represent themselves within social and political life. Their argument is that both parent-led, pro-cure groups (those who support treatments and potential 'cures' for autism) and self-representing, autistic person-led groups partially represent the autism community in general, and therefore the perspectives of both groups should be taken into account in considerations for autistic people with complex needs. In a

response to this paper, Chapman and Veit (2020) agree that it is important to involve the full diversity of autistic voices, though they contend that it is unhelpful to contrast autistic people with complex needs, who they term 'nonrepresenting autistics' (p.46), to those who are willing and capable self-advocates, termed 'representing autistics'. Instead, the authors argue that the discussion needs to include the autistic people who could be considered closer to nonrepresenting than representing, specifically referencing people who have been thought unable to communicate throughout childhood but who in adolescence, while remaining nonverbal, learn to competently communicate through typing, termed 'non-verbal self-representatives' (p.47) (they reference Higashida (2013) as an example). An argument is raised: on the one hand, pro-cure parent-led groups believe that non-verbal self-representing autistics are not severely disabled in the way that their children are and thus that anti-cure arguments from this group should not be taken into account. On the other hand, Chapman and Veit (2020) contend that non-verbal self-representing and nonrepresenting autistic people shared common experiences of disabling factors when growing up, and therefore it is non-verbal self-representing perspectives that should be prioritised in political and philosophical debate around nonrepresenting autistics. To do otherwise, Chapman and Veit argue, would be an act of 'epistemic injustice' (p.47) as it disregards the knowledge that non-verbal self-representative autistics have constructed through their lived experience of autism and disability. It is clear in these discussions that the knowledge of two separate epistemic communities – that of pro-cure parents and that of autistic self-advocates – is being pitted against one another on the issue of representation of autism *and* severe/profound learning disability, here termed nonrepresenting autistics, yet both arguments are void of reference to learning disability research, communities, cultures, and so on. This absence of reference suggests that Chapman and Veit, and McCoy et. al, are based in epistemic communities that do not draw from the learning disability field in their construction of autism. However, the learning disability field has a rich history of exploring advocacy and representation (see Brownlee-Chapman et al., 2018; Seale et al., 2015; Walmsley & Johnson, 2003) that has relevance through the scope of severe/profound learning disability. Accordingly, it is not just McCoy et al. (2020) that are risking 'epistemic injustice', but Chapman and Veit themselves.

Both Chapman and Veit (2020) and Cluley et al. (2020) are making an empirically based point that people with complex needs are not represented in the communities within which their diagnostic labels situate them, or within wider academic and political landscapes, and subsequently describing changes that may help to overcome such exclusion. This is what Vehmas and Watson (2016, p. 4) refer to as the 'strong normative dimension' of disability studies, which is that life for disabled people will improve if academics can 'identify and challenge what are seen as discriminatory practices and beliefs'. So for Cluley

et al. (2020), the adoption of the social model of disability must be challenged as it is seen to discriminate against people with learning disabilities and complex needs, while for Chapman and Veit (2020), who can represent autistic people with complex needs must be challenged, due to ethical implications of pro-cure/pro-treatment groups having priority in social and political discussions. The issue for Vehmas and Watson (2016, p. 5) is that the normative dimension of disability studies produces arguments that 'typically insinuate how things, as they currently stand, are wrong whilst providing very little practical ethical guidance as to how things ought to be'. Here for example, Chapman and Veit (2020) and Cluley et al. (2020) make a normative assumption that it 'ought not be the case' that people with complex needs, those considered in relation to the terms 'autism' and/or 'learning disability', have minimal representation in academic and political life, though their subsequent suggestions are of no clear practical use in remedying the issue. 'Oughts', Vehmas and Watson (2016, p. 5) contend, often carry 'little or no evaluation as to why they are classified as such', so from a disability studies perspective it is quite appropriate to acknowledge the injustice of the marginalised position of people with complex needs: it is a normative assumption. However, what Chapman and Veit (2020) and Cluley et al. (2020) fail to explicitly address, is why people with complex needs cannot represent themselves in such regards. Instead, they perpetuate the normative, ableist notion that has underpinned disability studies since the social model of disability was conceived: that people with complex needs are incapable of participating and expressing themselves within academic or societal processes (see Mietola et al., 2017, p. 266).

4.2 Evaluating the 'ought' of representing autism, severe/profound learning disabilities and complex needs from a lifeworld-life conditions perspective

A question relevant to the discussion of representation was asked by Chown and Leatherland (2020): 'Can a Person be 'A Bit Autistic'?', which they posed in response to Happé and Frith (2020, p. 6) who had claimed that this was the case in an annual review of autism research. In viewing autism at the behavioural level – as a collection of traits that signify an autistic being – Happé and Frith (2020) contend that some people may have a number of such traits though not enough to be considered autistic, and thus they can be understood as 'a bit autistic' (p.6). They subsequently support this from a genetic perspective as genetic influences on autism are evident in members of the population not diagnosed with autism (see for example Creese et al., 2020). For Chown and Leatherland (2020), viewing autism as a collection of behavioural traits misses the underlying reasons for those behaviours, that being 'the possession of a particular neurological/cognitive type/style' coupled with 'experiencing the social and physical environment in a qualitatively different (to non-autistics) way'. Anyone can act or behave in a way similar

to that related to autistic persons, but this does not mean that they are experiencing their world in an autistic way. The danger in viewing autism as a collection of traits, Chown and Leatherland (2020) maintain, is that people who do not demonstrate their autism through their behaviours, but that qualitatively experience life as autistic, may not be provided the opportunity to identify as autistic, or to speak, act or live as a member of the autistic community. This argument focuses the issue of representation on to experience and the significance of those who have particular experiences of the world being afforded the opportunity to represent their particular perspectives. In one regard, this appears to support the aforementioned views of Chapman and Veit (2020) as 'non-verbal self-representing' autistic people share or shared similar experiences to 'nonrepresenting' autistic people during childhood, as well as aspects of neurological and biological makeup, thus positioning them as appropriate representatives of this part of the autistic community. This contention is however akin to claiming that 'non-verbal self-representing' autistic people are 'a bit severely/profoundly learning disabled' as they have or had similar characteristics, traits or circumstances to people (considered autistic or not) with severe/profound learning disabilities, which as Chown and Leatherland (2020) acknowledge in relation to the term 'a bit autistic', risks denying related people of the right to represent their own perspectives and identities.

Shared experience is also an important factor in the concept of autism put forward by Belek (2019) who, drawing from Latour (2005), argues that taking the perspective of the social model necessitates that all structures that constitute autism should be considered valid, including 'biological ties... cognitive ties... sociological ties... epistemic ties... affective ties... and, indeed, social ties' (p.235). Belek acknowledges that all such structures will change over time and according to context, with each change affecting the overall notion of autism. From here, the author goes on to argue that 'autism is the abstracted collection of traits... that emerge from a matrix of biological and societal factors and that are shared in various forms and to varying degrees by some people but not others...' (p.236). The author subsequently separates autism into two interrelating entities – the term 'autism' and, autistic people - and so, Belek (p.231) argues, 'the category of autism emerges from the shared experience of those labelled autistic, but is wholly irreducible to them' (p.231). A metaphor of autism as a piano is given (p.239), with each trait representing a key that when played as a chord signifies the embodied experience of an individual autistic person. Like Chown and Leatherland (2020), Belek is asserting that though autistic people are heterogeneous, with diverse characters, lifestyles, abilities, personalities and so on – they share in an assemblage of neurological, biological and social factors which presupposes them to experiencing the world in a similar manner.

Although not specifically aimed at the issue of representation, the arguments of Belek (2019) and Chown and Leatherland (2020) both point towards the significance of underlying neurological/cognitive factors and shared experience when considering who autistic people are, and therefore, who should be listened and responded to in academic, political and cultural life. To draw from this in the context of autism and severe/profound learning disability, one is able refocus the meanings of the terms away from any fixed definition and towards the shared experiences of those identified as so. This is a shift towards 'people's actual life-worlds, of which neurological functioning and cognitive and sensory processing are indeed significant factors, but are never isolated from others, equally crucial aspects of being in the world' (Belek, 2019, p. 238). 'Lifeworld' refers to the subjective way in which each person experiences reality though 'promoting and limiting' (Kraus, 2015, p. 5) this is their life conditions – 'the material and immaterial circumstances of life' (Kraus, 2015, p. 4). For people with complex needs, the separate diagnoses of autism and severe/profound learning disability may, at times, lead to dissimilar experiences as a consequence of research, culture or policy relating to one term or the other – yet on the whole, the structural guidance of educational policy, social care and so on are likely to result in markedly similar life trajectories. Such structures necessarily mean that autistic people and/or people with severe/profound learning disabilities, those identified as having 'complex needs', share experiences – lifeworlds – perhaps more so than any other 'group' of persons that identifies/is identified in relation to the terms autism and learning disability. This is inevitable as their subjective experiences are confined to the spaces deemed necessary for their existence, such as special education needs schools, day services and residential services. These can be understood as the 'limiting' (Kraus, 2015, p. 5) and shared life conditions of people with complex needs: a key and defining factor in how they experience the world, the opportunities they are afforded, and the lives they lead.

In acknowledging the relationship between lifeworlds and life conditions, people with complex needs can be seen within the wider communities that their diagnostic labels situate them within – it is part of their life conditions – yet it also obliges an acknowledgement of their particular life conditions and how this may relate to their lifeworlds. An autistic way of experiencing the world may be synonymous across the autism community, as Chown and Leatherland (2020) assert, but not all have to 'withstand within the context of the...' same 'given social and material conditions' (Kraus, 2015, p. 4). Through this perspective, it is possible to situate the terms 'autism', 'severe learning disability' and 'profound learning disability' within a shared space relevant to people with complex needs and the life conditions that they share. This space, which can be termed 'autism and profound learning disability', is one of marked marginalisation as highlighted in the literature review (Chapter two). The experiences of people related

to the space of autism and profound learning disability will be subjective and diverse, it is the nature of lifeworlds, however there will inevitably be fundamental issues and phenomenon relevant to their experiences as these are subject to the life conditions that they are part of and surrounded by. From here, the 'oughts', how things *should* be according to the 'normative dimensions' of disability studies (Vehmas & Watson, 2016, p. 4), can be assessed with relevance to the particular life conditions of those within the space: how they experience the 'material and immaterial circumstances of life' (Kraus, 2015, p. 4) including their surrounding social and cultural environments, their abilities and impairments, the disabling conditions that surround them and the commonalities they may share with the wider autism and learning disability communities.

In a recent review of the transition of disabled people from institutional care to community based services in Europe, Šiška and Beadle-Brown (2020, p. 15) state that 'The role of research is critical..., especially to create a body of research that is independent from the agendas of policy makers, service providers and other stakeholders. However, in order for this to be possible, *clear definitions and shared terminology and understanding* (emphasis added) are important.' Similarly, in the end of his discussion on the meanings of autism, Belek (2019, p. 239) remarks, 'If the social study of autism—or indeed, of any other social category—is to have significant influence in leading public and academic discourse, shaping research priorities, and informing policy decisions, it needs to be able to define its object of study independently.' An argument could be made, as Bellamy et al. (2010) suggest when trying to define PMLD, that there is a need for clear definitions of 'autism level 3' and 'severe learning disability' and 'profound learning disability' and 'PMLD', so that people in these groups can be better identified, understood, heard, and responded to. However, if better representation of people identified under these labels is a key aim, then separating them only serves to further marginalise their voices. Researchers that work in relation to only 'autism', or only 'severe/profound learning disabilities', or only 'PMLD', are creating barriers between a broad group of people with complex needs, who are rarely represented or given opportunities to speak for themselves. Academic outputs, conferences, papers, books, journals, which focus on one diagnostic term while disregarding others, are weakening the collective voice of a group of people who share needs, characteristics, circumstances and ways of living. The space of autism and profound learning disability represents these shared life conditions, and recognises related people as acutely marginalised from societal, academic and political discourse. In recognising this as such, the space aims to bring together their perspectives, experiences, values and customs, so they can be considered and learned from through research practices that, through development, are relevant and appropriate to their circumstances. To do otherwise is both epistemically and ethically unjustified.

The assertion that a space of autism and profound learning disability can provide benefit to the lives of related people is what earlier was referred to as an 'ought' (Vehmas & Watson, 2016, p. 3), as it adheres to the normative dimension of disability by locating a problem (the marginalisation of autistic people with profound learning disabilities) that quite apparently requires addressing. The above discussion, as well as the findings from the literature review, have provided an evaluation as to why the terms *are* currently classified separately, and why they *ought* to be considered in a shared, academic space. To make this a worthwhile task, according to Vehmas and Watson (2016, p. 5), the next step must be to provide 'practical ethical guidance' and so this is what will be addressed in the following section.

4.3 The practical implications of a space of autism and profound learning disability

The consequence of academia developing to the exclusion of autistic people with profound learning disabilities is that the methodologies, methods and tools commonly used to research are often inadequate in the context of the communicative styles and knowledge capacities of related people (Simmons & Watson, 2014b, p. 148). In the holistic sense of Nelson's epistemology (Nelson, 1993), there is limited understanding of how to define and locate evidence that is ethically justified in constructing knowledge in the space of autism and profound learning disability. In recognising the significant marginalisation of autistic people with profound learning disabilities, it is possible to introduce one broad, overarching principle to the space of autism and profound learning disability, and that is for research to be developed from an inclusive standpoint. Inclusive research is an approach that has been developed to democratise research for people who have been, and continue to be, excluded or ignored (Nind, 2017). The term identifies research in which participants are in a position to represent their own voices (to greater or lesser extents) and variations can be found within numerous areas such as feminist or youth research (e.g. Coghlan and Brydon-Miller (2014) and Ozer and Wright (2012) respectively). Although many methodologies exist under the umbrella term 'inclusive research', such as 'emancipatory' or 'participatory', it could be argued that they all share a primary aim to begin to equalise the power imbalance that pervades research, that which exists between the researchers and the researched (Walmsley & Johnson, 2003, p. 10).

The autism and learning disability research fields have researchers that promote and work within inclusive frameworks, though the learning disability field has a longer and richer history of inclusive research than that of the autism field (Nind, 2017). More recent years have seen the autism field become increasingly aware of the values of inclusive research - mainly a result of autistic researchers highlighting

the inadequacy of autism research without autistic voice (Milton & Bracher, 2013) – resulting in discussions and theories concerned with what inclusive autism research is or should be (Chown et al., 2017; MacLeod, 2019), as well as the development of a number of inclusive autism studies (e.g. MacLeod et al., 2014). Attention has been paid to what inclusive research may mean for autistic (Pellicano (2017a) and non-autistic (Seale et al., 2015) people with profound learning disabilities, and there is now small number of studies involving people from this group that could be considered inclusive (e.g. Gaudion (2015) and Simmons and Watson (2014b)).

Although these positive developments are increasing opportunity and participation for autistic people with profound learning disabilities within research, it remains that research practitioners commonly work from the perspective of one term or the other. So for example Simmons and Watson (2014b) developed a methodology for researching the social experiences of people with profound (and multiple) learning disabilities within educational settings, while Susie Ridout (Ridout, 2016, 2017; Ridout, Guldberg, & Macleod, 2011) developed a narrative methodology for researching the support experiences of autistic people (that may be considered to have profound learning disabilities) within day services. Both methodologies are capable of exploring the experiences of autistic people with profound learning disabilities though they have been developed through the separate framing of autism and profound learning disability, meaning that it is unclear as to the appropriateness of one or the other if attempting to research in ways that are inclusive of both terms and their related communities.

In arguing for the merit of recognising and bringing together the values and perspectives of autistic people and people with learning disabilities in an effort to work inclusively for autistic people with profound learning disabilities, a link emerges to the ‘third space’ of inclusive research (Seale et al., 2015). The ‘third space of understanding’ was conceptualised by Hall (2014, p. 384) as a site for continued negotiation and development for western academics seeking to research with Indigenous people in ways that are respectful and understanding of their ontologies. Different groups have different perspectives on what is appropriate and meaningful research practice, such as how academics should act, the extent to which they want to be involved or the areas that they want research to focus on. Effective and sensitive methodologies may result from researchers working extensively with one group, yet these methodologies may be inappropriate for research with another group, or with another set of individuals from the same group. In recognising how the social, cultural and political values of different groups intersect, and in contributing these understandings to a shared space, researchers have the opportunity to improve research practices for those people their work seeks to benefit.

The concept of the third space has emerged as relevant in the conceptualisation and development of both inclusive learning disability (Seale et al., 2015) and autism (Andrews et al., 2019; Bertilsdotter Rosqvist et al., 2019) research. To first take the former, Seale et al. (2015) held a series of seminars concerned with improving inclusive research practices and participation for people with learning disabilities, including in the discussions researchers with and without learning disabilities, people from the learning disability community, family relations and practitioners. During this, it was recognised that for inclusive research to continue to develop, researchers from traditionally separate fields must work together to promote and advance its standing. Besides raising awareness of the benefits of inclusive research to funders, ethics boards and the wider research field, inclusive researchers that work within a shared space have the opportunity to negotiate and explore the complexities of intersectionality, identifying and creating methodologies and methods that are respectful and appropriate to the particular circumstances of members of the learning disability community. In a similar fashion, a paper by Bertilsdotter Rosqvist et al. (2019) formed through meetings and discussions (online and face to face) involving autistic and non-autistic researchers that aimed to explicate the epistemological implications of developing emancipatory autism research. The third space was put forward as a relevant concept as it emphasises the need for researchers (autistic or not) to work in ways that are respectful of their participants' culture and perspectives, including identifying appropriate topics, engaging in reflexive practice, acknowledging epistemic power dynamics and facilitating open and safe discussions (Bertilsdotter Rosqvist et al., 2019, pp. 1091-1092).

In relation to profound learning disabilities with the third space, Seale et al. (2015, p. 487) propose that meaningful research participation involves researchers working in partnership with related people and their social (family and friends) and support (social and health care professionals) circles, henceforth termed as 'research collectives'. This approach seeks to recognise and utilise the understandings that develop between people with profound learning disabilities and those they are closest to over the course of their lifetimes. For example, Andrews et al. (2019) describe and detail a study exploring the developing sexuality of young autistic men with profound learning disabilities that, due to ethical boundaries, could not directly participate in the study; though, by utilising the knowledge of a research collective, the study was enabled and the perspectives of the young men were communicated by their family relations. Practitioners within the third space thus identified and shared a way of working that was appropriate to the particular circumstances of the participants and this can be considered a step towards inclusive practice.

To propose that working within a research collective is appropriate to the development of research within the space of autism and profound learning disability requires ethical consideration as the views and perspectives of relations and carers do not always coincide with young disabled people (Garth & Aroni, 2003). The following section will therefore explore theory that is relevant to both the autism and learning disability communities to assess how involving family members and support circles may impact research involving autistic people with profound learning disabilities.

4.4 The double empathy problem and inclusion phobia

Researchers that interpret autistic people – either themselves or through the people that know them - create issues relating to the construction of ‘autism’ by a non-autistic majority: what has been termed the ‘double empathy problem’ by Milton (2012a) and the ‘cross neurological theory of mind’ by Beardon (2017, p. 16). To put this into context, autistic people have been said to lack theory of mind (see Baron-Cohen, 1991; Jolliffe & Baron-Cohen, 1999; Rutherford, Baron-Cohen, & Wheelwright, 2002) - the ability to attribute mental states to others – that has resulted in the perception that autistic people lack empathy. Although the methods used to research theory of mind in autistic people have been critiqued to show a lack of external validity (Brownlow & O'Dell, 2009) - and new studies have emerged that have found no differences in theory of mind between autistic and non-autistic peers (Scheeren Anke, de Rosnay, Hans, & Begeer, 2012) - the results have nonetheless shaped how autistic people are understood (McDonagh, 2013).

The double empathy problem (Milton, 2012a, p. 884) contends that a non-autistic society has attributed a lack of empathy – as well as a number of other unifying theories (see Milton, 2012b) - to autistic people for not conforming to social norms, yet it is in fact a two-sided issue caused by misunderstandings between two ontological states. Autistic people are forced to adapt to the demands of the dominant non-autistic society or, if unable, are treated as a medical condition/disorder (Brownlow, 2010; Chown, 2014, p. 1675). By contrast, impairments typically related to autism – those in communication, behaviour and socialising - are reported to disappear when autistic people engage with each other in autistic space (material and immaterial environments designed by autistic people for autistic people) (Bertilsson Rosqvist, Brownlow, & O'Dell, 2013; Chown, 2014, p. 1673).

The double empathy problem is now supported through empirical evidence. For example, non-autistic people can misunderstand the behaviour of autistic peers (Edey et al., 2016; Sheppard, Pillai, Wong, Ropar, & Mitchell, 2016) and they may also make negative judgements based on initial impressions of social behaviour (Sasson et al., 2017). Difficulties also lay in family relationships: Heasman and Gillespie

(2017) developed an innovative two-sided methodology to examine how 22 autistic person and family member dyads thought about themselves and each other and the results suggest that, when compared to how the autistic person views themselves, non-autistic family members over attribute autistic traits to their autistic relation. This indicates that family members create expectations of autistic relations built around societal expectations of what autism *is* and this is exacerbated by differences in communication (Heasman & Gillespie, 2017, p. 8).

Although studies are beginning to increase understanding of how autistic and non-autistic people engage with and understand each other, their scope is limited to interactions between people in similar circumstances (e.g. ages (Sasson et al., 2017), locations (Edey et al., 2016) or IQs (Crompton, Hallett, Ropar, Flynn, & Fletcher-Watson, 2020)). If the construct of autism filters down to interactional behaviour (Hacking, 1995), it would suggest that other intersectional labels/identities – such as gender, culture or disability – can also affect how autistic people understand non-autistic people, and vice versa (see O'Dell et al., 2016). In the context of this study, learning disability must therefore also be of consideration. Interestingly, issues highlighted in the double empathy problem are similar to that found in 'inclusion phobia' (Goodey, 2015, p. 9): a theory that suggest discourses around learning disability are constructed to other people with the label due to a societal phobia of people who challenge what it is to be human. Goodey presents this theory from a historical perspective by detailing the various ways that people with learning disabilities have been excluded from societal life, such as through their incarceration in institutions (see Jackson, 2000). Exclusionary practices and structures remain in the contemporary context, so consideration of the nature of education for people with learning disabilities (see Slee, 2019) highlights how inclusion phobia has been realised within societal organisation: people labelled as such are quite literally separated from 'the mainstream' into 'Special Education Needs' schools. These 'othered' sites are maintained by wider society through discourses that either emphasise the vulnerable or challenging nature of people with learning disabilities (Goodey, 2015, p. 9). There is for example, research (O'Byrne & Muldoon, 2019) into the construction of learning disability within special education needs schools that suggests that both teachers and parents emphasise discourses in which children labelled as so are seen as too vulnerable to make their own decisions, so not only are they isolated from mainstream educational settings but so too are they made incapable of exercising autonomy within these 'safer' environments.

A shared theme of inclusion phobia and the double empathy problem centres on collectives of people that do not identify as autistic or with a learning disability defining those that do or that are labelled as so. The inherent bias in this dynamic inevitably favours the majority as they construct

knowledge from their perspectives, according to their experiences: ‘we construct ideas, hypotheses, theories, and models, and as long they survive, which is to say, as long as our experience can be successfully fitted into them, they are viable’ (Von Glasersfeld, 1981, p. 4). According to this, it makes sense that those working towards inclusive autism (Ridout, 2017, p. 53) and learning disability (Atkinson, 2004; Brownlee-Chapman et al., 2018; Cluley, 2017; McCormack, 2017; Owens, 2007; Stefánsdóttir & Traustadóttir, 2015) research advocate for methodologies that include voices from a diverse range of autistic and non-autistic people with learning disabilities, as they argue that this could help transform the labels to represent their own perspectives. The etic perspective – that of the clinical outsider – can be overcome through the emic perspective – that of the attentive insider (Andrews et al., 2019; Gillman, Swain, & Heyman, 1997; Goode, 1992), ‘not by seeking global coherence, but by celebrating those small, radiant moments of insight and purity that reminds us of our shared humanity’ (Osteen, 2013, p. 280). However, to seek to garner the diverse perspectives of autistic people with profound learning disabilities by working with research collectives – the social and support circles of participants – suggests a practical dynamic that shares the conditions that have perpetuated the double empathy problem and inclusion phobia. In essence, groups of people that do not identify as autistic with learning disabilities determining how the perspectives, lives and experiences of those labelled as so are understood which, as the aforementioned research (O’Byrne & Muldoon, 2019) into the discourse of parents and teachers within special education needs schools demonstrates, may not be appropriate even where relationships are close and the emic perspective is enabled.

It is unclear whether the theoretical insight that the double empathy problem and inclusion phobia offers may help or hinder the development of ethically sensitive research in the space of autism and profound learning disability – it may be what Vehmas and Watson (2016, p. 4) term another ‘ought’ that outlines a problem supported by theory that provides minimal practical use. In the next part of the methodology, the issues raised in relation to the two theories will be considered as a methodology is developed to explore day service culture, with particular attention to how research collectives may be involved the research and how this may impact the participation of autistic people with profound learning disabilities.

4.5 Methodology Part One Summary

The first part of chapter four began by exploring the current representation of people with complex needs in relation to the terms ‘autism’ and ‘severe/profound learning disability’. This was to address a study objective relating to the development of a methodological approach: that is, to provide understanding of

the ethical implications of viewing the terms as synonymous or separate when developing research for autistic people with profound learning disabilities. As it was concluded that it is both ethically and epistemically unjustified to separate the terms, an academic space of 'autism and profound learning disability' was conceived using the phenomenological concept of life-conditions (Kraus, 2015). This space is a key contribution of this thesis, as it represents a way to develop and promote research practice that can challenge the exclusion of autistic people with profound learning disabilities from academic processes. The intention is that methodological and empirical contributions to the space can seek to challenge the misconception that autistic people with profound learning disabilities are incapable of communicating or expressing their perspectives. In doing so, the voices of autistic people with profound learning disabilities may receive greater attention in wider social and political discourses. Importantly, the space provides a way to identify research that is relevant to people with complex needs, those related to the terms autism and severe/profound learning disability, so that researchers can better understand the impact of policy and services 'on people's lived experiences in terms of choice and control, inclusion, and participation' (Šiška & Beadle-Brown, 2020, p. 4).

The first part of chapter four concluded through consideration of the third space of inclusive research (Seale et al., 2015), specifically, a potential method that involves researching with autistic people with profound learning disabilities and their social and support circles. It highlighted two theoretical perspectives that require consideration if developing research that includes such methods: the double empathy problem (Milton, 2012a) and inclusion phobia (Goodey, 2015). Moving forward, the second part of the chapter will keep such concerns in hand as a methodology is developed, exploring how they may be addressed and how this may impact the practicalities of conducting research that explores the experiences of autistic people with profound learning disabilities.

Chapter Four – Methodology – Part Two

Developing an Ethically Sensitive Methodology

The second part of chapter four addresses a key aim of this study by contributing a methodology to explore the everyday experiences of autistic people with profound learning disabilities. The purpose of this was to establish a way to research service culture in way that can account for the roles, perspectives and contributions of autistic people with profound learning disabilities, which, as suggested in the literature review (Chapter 2.5), takes place in the everyday. To begin the chapter, the methodology is given a clear epistemological basis. This includes drawing from concerns raised in the first part of the chapter, such as those related to the double empathy problem (Milton, 2012a) and inclusion phobia (Goodey, 2015). Once an epistemological foundation is established, a discussion is presented on the theoretical and practical ways in which to research the experiences of autistic people with profound learning disabilities, with reference to the related field of phenomenology and inclusive learning disability and autism studies. It concludes by presenting a novel methodology that is argued to hold inclusive value in the space of autism and profound learning disability as it enables researchers to adapt research and its processes, such as methods and theoretical perspectives, to the individual circumstances and experiences of participants.

4.6 Research context

To state clearly but briefly the research concept, for ‘methodological considerations are only meaningful in the context of specific research proposals’ (Christensen & Jensen, 2012, p. 113 referencing Staunæs & Søndergaard, 2006):

The concerned topic of this study is *day service culture* which it seeks to explicate from the perspective of autistic adults with profound learning disabilities. The literature review into service culture suggested that service people shape and experience culture within the context of *everyday life at day services*, and so this is the phenomenon that the methodology was developed to investigate. This phenomenon inevitably relates to, and includes, other people, such as support workers and autistic people without learning disabilities, though it is the experiences of autistic people with profound learning disabilities that are of key concern. This is an intentionally broad phenomenon due to the lack of qualitative research previously done with autistic people with profound learning disabilities so therefore, the focus of the research may develop if new insights are gained over its course.

4.7 Constructionism in the third space

The philosophical underpinnings of a study provide rigour to the methodological direction it can take and if not adhered to, the ‘findings may be shown to lack authenticity and credibility’ (Appleton & King, 2002, p. 647). To address this, researchers refer to ontology – the study of being, existence and reality – and epistemology – the study of knowledge (Pernecky, 2012, p. 1121). In the case of this study, the methodological direction was underpinned by a constructionist epistemology and a critical realist ontology, as described by Levers (2013, p. 2). This sees all knowledge as constructed by an individual and their interactions with others in a social world, providing them with access to an ontological reality from their subjective positions.

There are, as Pernecky (2012, p. 1117) points out, different categories and modifiers related to constructionism, such as ‘radical, critical, cultural, social, material, cognitive, scientific, realist, naturalistic...’ and more. One particular area Pernecky (2012, p. 1132) discusses is the difference between constructionism and constructivism. He refers to a number of different constructionist theorists (Crotty, 1998; Hollinshead, 2006; Lynch, 1998; Schwandt, 1994; Von Glasersfeld, 1984), stating that constructivism concerns attempts to ‘examine the meaning-making activity of the individual mind’ (Pernecky, 2012, p. 1121) while constructionism refers to such processes of a collective sort. They are both constructionist but guide different kinds of research approaches. As I will detail below, this is worth consideration when seeking to develop methodologies in the space of autism and profound learning disability, as it will guide different ways of working with autistic people with profound learning disabilities and, as I have argued is important (Chapter 3.4), their social and support circles.

A key notion of inclusive research is that of meaningful participation for those people with whom the research is concerned (Walmsley & Johnson, 2003, p. 26): ‘Nothing About Us Without Us’ (Charlton, 2000, p. 14). Approaches that are underpinned by a constructionist epistemology necessarily go some way to achieving this as the researcher is acknowledging that the knowledge construction, of whatever sort, is contributed toward by themselves and participants. What is pertinent in the case of inclusive research at the intersection of autism and profound learning disability is whether the approaches are guided by constructionism or constructivism: on the one hand, constructionism aligns to the third space of inclusive research as it provides a platform for researchers to listen to autistic and non-autistic people with profound learning disabilities through the construction of a research collective. On the other hand, one could argue that this approach to knowledge construction has perpetuated the conditions that underlie the double empathy problem and inclusion phobia: the majority has collectively constructed those who

are identified as autistic with profound learning disabilities as a deficit and thus their realities are shaped and experienced in accordance with this knowledge.

The book, *The PMLD Ambiguity: Articulating the life-worlds of children with profound and multiple learning disabilities* (Simmons and Watson, 2014), details a study guided, in part, by a constructionist epistemology that explores the experiences of Sam, a child with profound learning disabilities. Although not referenced as contributing to the third space of inclusive research, its publication was prior to Seale et al. (2015), the approach utilised Sam's social and support circles as a way to understand his idiosyncratic communication. During fieldwork, the researcher sought input from those around Sam, both separately from Sam through focus groups and with Sam during participatory observations. The meaning of Sam's world was understood as a collectively agreed-upon construction drawn from the interplay of interpretation that existed within the research collective (Simmons & Watson, 2014b, p. 135). Simmons and Watson (2014b, p. 136) argue against a constructivist approach as it is said to strengthen the researcher's interpretation of the participant and ignores that of their social and support circles: a clear issue in the inclusive field where attempts should be made to reduce the power imbalance that exists between researchers and researched (Walmsley & Johnson, 2003, p. 32).

One way to address Simmons' and Watson's concerns of constructivism in the third space is to position members of the research collective alongside the researcher as fellow and equal constructors of the participant, providing a situation in which their idiosyncratic communication is understood from each individual perspective, as opposed to a collective but imbalanced (non-autistic to autistic, learning disabled to non-learning disabled) viewpoint. As Simmons and Watson (2014b, p. 136) state, 'different people construct the child in different ways based on their experiences of, and with, the child'. On the one hand, methods guided by a constructivist approach would seek to keep these constructions distinct, to 'examine the meaning-making activity of the individual mind' (Perneky, 2012, p. 1121), perhaps with observations of a participant conducted only by the researcher, or only by a co-researcher. On the other hand, a constructionist approach, as demonstrated by Simmons and Watson (2014b, p. 153), combines these different perspectives within a method, such as through a focus group or through joint observations, creating an agreed upon construction of the participant. There is potential for merit and fault in both of these approaches. For example, the opportunity to explore individual constructions could illuminate aspects of meaning and experience that may be overshadowed through collective construction. Certain people may feel less inclined to speak up during focus groups or if they disagree with the researcher's perspective during observations, while they may feel more confident to put forward their interpretation if working one-to-one with the participant. In contrast, discussion between research collectives can

prompt new interpretations or alternative perspectives as to the meaning of communication and experiences of people with profound learning disabilities (Simmons & Watson, 2014b, p. 157). Furthermore, the practical implications of organising data collection for a number of family members or support workers may mean that some do not get any input and their interpretations are subsequently discarded in favour of a few individuals. The extent to which members of research collectives can commit their own time also raises questions as how to define their roles: what constitutes a 'co-researcher'? And how is this participation meaningful rather than tokenistic? (see Liddiard, 2013, p. 7).

Whether it is possible to adhere to a constructivist epistemological approach within the third space is debatable due to the inevitable impact of the researcher on the study's direction, processes and dissemination. For example, if members of a research collective work individually with a participant with profound learning disabilities, who is it that analyses the related data? And who decides on an appropriate analytic method? Is there an inevitable three-way construction between the person with profound learning disabilities, the co-researcher and the primary researcher? These questions highlight the tenuous relationship between constructivism and constructionism, particularly when working in the third space and attempting to facilitate research processes that are meaningful for a research collective but that also acknowledges their circumstances within the research, such as whether they are taking part in a paid capacity or otherwise. This is a consequence of developing inclusive research practices that are appropriate for different people in different circumstances – it opens up 'messy spaces' (Seale et al., 2015, p. 489). Both inclusive autism (Fletcher-Watson et al., 2019, p. 948) and learning disability (Callus, 2019; Hollingworth et al., 2012; Marshall & Tilley, 2013; Seale et al., 2015, p. 491) fields have recognised that research practice should involve on-going negotiations between researchers, participants and their related communities – 'flexibility, responsivity and creativity' (Brownlee-Chapman et al., 2018, p. 891). This is an effort to ensure that design, developments and changes in research remain appropriate and relevant to the concerns of the participants. Constructivism then could perhaps be seen as an initial goal for research in the space of autism and profound learning disability, something that can guide study design but that requires consideration during and assessment after to understand the extent to which individual constructions were facilitated.

To summarise, the methodology developed to explore day service culture in this study emanated from a subjectivist, constructionist epistemology and a critical realist ontology. The type of constructionism it aimed to focus on is that of constructivism - the 'meaning-making activity of the individual mind' (Perneky, 2012, p. 1121) - which was an attempt to minimise the conditions that contribute to the double-empathy problem and inclusion phobia. The study design therefore included

methods in which members of a research collective could individually contribute towards an understanding of the experiences of young autistic adults with profound learning disabilities at day services. I would argue that this approach has the potential to unearth diverse interpretations that may be lost through methods in which collective constructions are emphasised, such as focus groups. While this was the intention, it is also acknowledged that constructivism can lean towards constructionism at times as new and unforeseen spaces open, and so the methods used are given consideration and assessment in the second part of Chapter Six: 'The *While* of Participation in the Space of Autism and Profound Learning Disability' (p.150).

4.8 *A phenomenological direction*

In defining epistemological and ontological assumptions, the concern turns to the third objective of the methodological development: to find ways of researching experience that is appropriate to the circumstances and communication of autistic people with profound learning disabilities. Experience suggests a phenomenological approach though phenomenological approaches come in different sorts, each with their own particular assumptions and arguments as to why they may be appropriate and beneficial to researchers and their aims. These approaches are often categorised within the two broad schools of phenomenological thinking that originated in the first half of the 20th Century, that of the descriptive and the interpretive (hermeneutics). These sought to challenge the 'dishonest' positivist perspectives that dominated science, 'because they take for granted, without explicitly mentioning it, the other point of view, namely that of consciousness, through which from the outset, a world forms itself around me and begins to exist for me' (Merleau-Ponty, 1962, p. ix). The works of Husserl and Heidegger referenced below are later translations.

The descriptive school emanates from the philosophical notions of Husserl (1970a) who contended that there is value in rigorously researching experience as a scientific endeavour. Biology was inadequate for Husserl (1970a, p. 6) as it could not account for the 'subjective element' that 'guides everything in the world that we call organic life'. It was this subjective, prereflective experience that the descriptive school was concerned with, believing it to have essential features that could be understood in relation to specific groups of people. In ascertaining commonalities in the experience of a phenomenon, it is thought that these features can come to represent the phenomenon's true nature (Lopez & Willis, 2004, p. 728). This is independent of historical, cultural or societal contexts, as these experiential features would be there for any person that experienced the phenomenon: they are reality. As such, researchers working in this tradition seek to discard knowledge of wider contexts or relevant theory and, in what's

termed the epochē, instead orientate themselves toward how the phenomenon presents itself to consciousness as it does in everyday life, through the 'natural attitude' (Giorgi & Giorgi, 2003, p. 178).

The interpretive, or hermeneutic, tradition originates from a student of Husserl, Martin Heidegger (Lopez & Willis, 2004, p. 728). Hermeneutics is the 'art of understanding' (Zimmermann, 2015, p. 2) and happens as part of everyday experience as it is integrated into our life contexts. Heidegger (1962) terms this our *being-in-the-world* to describe how our lived realities are inextricably linked with the world around us. In contrast to the descriptive school in which consciousness of the individual is autonomous (Türker, 2013, p. 626), hermeneutics finds humans embedded in the conditions of everyday life by which their choices are confined. The complex integration of life and world directs researchers towards an approach in which they look for 'meanings embedded in common life practices' (Lopez & Willis, 2004, p. 729). The process of assuming the epochē is considered unattainable, so the preconceptions of the research context should be acknowledged and where necessary, adopted within research processes. The meanings of phenomenon that arise from research in the interpretive tradition are considered a fusion of understanding between the researcher and the participant as they meet in time and space in ways that are both subjective and shared (Koch, 1999, p. 31).

Although these phenomenological schools have given rise to methodologies that adhere to the tenets of their particular philosophies, they are not mutually exclusive and can be understood as 'a continuum with different researchers valuing more highly one or other side of the spectrum' (Finlay, 2011, p. 110). Similar to the way in which the philosophical principles of epistemology and ontology should guide a study, making clear the phenomenological underpinnings is important to understanding what can be asked of a phenomenon within a study context. In the case of the present study, it is useful to refer to the aforementioned phenomenological, constructivist perspective of Kraus (2015) and the concepts of lifeworlds and life conditions. The phenomenological concept of intentionality states that experience is an amalgam of the *noesis* – the form of consciousness (e.g. perception or memory) – and the *noema* – the thing (e.g. an event or object) - and this experience is given meaning through the subjectivity of the lifeworld (Ashworth, 2016, p. 22). One can never transcend the lifeworld - as Ashworth (2016, p. 22) points out, Heidegger (1962) thought of world and lifeworld as synonyms. Kraus (2015, p. 3) agrees with this notion, as he also argues that we can never access the noesis and noema as they happen, intentionality is 'operationally closed'; however, this does not deny the existence of a single reality, but means that we can only access a particular area of it through our subjective relationship with it. For Kraus (2015, p. 4), the lifeworld refers to our subjective reality but this is aligned to an ontological reality and limited by our life conditions – the personal 'material and immaterial circumstances of life'. This description tends

towards the interpretive tradition through its acknowledgement of contextual factors in a person's day-to-day experiences, though it also borrows from the descriptive school to recognise the subjective 'lived-through meaning of experience' (Ashworth, 2016, p. 21). Here, at this interpretive/descriptive position, it is possible to explore the experiences of autistic adults with profound learning disabilities – their lifeworlds – while also attending to the specific circumstances that situate them within the space of autism and profound learning disability – their life conditions.

4.9 An approach for exploring experiences of everyday life

Methodologies developed to explore the experiences of autistic people with profound learning disabilities primarily aim to facilitate this through creative or visual approaches such as collage and narrative diaries (Ridout, 2016, 2017; Ridout et al., 2011), talking mats (Stewart, Bradshaw, & Beadle-Brown, 2018) and multi-modal approaches (Doak, 2018), though these remain inaccessible to persons who communicate through body language and vocalisations and, for Simmons and Watson (2014b, pp. 143 - 144), may risk tokenism due to the significant input required from researchers, family members or carers. Elsewhere, life story work has been successful for people with profound learning disabilities documenting their experiences across significant periods of time (McCormack, 2017). From a phenomenological perspective (Berndtsson et al., 2007, pp. 269 - 270), narrative approaches should be used if participants express their experiences through narrative formats, such as when Öhlen (2003) introduced a narrative approach to a study after finding that people in palliative care communicated their experiences of suffering through narrative formats. In the case of the everyday experiences of autistic people with profound learning disabilities within day services, it was unclear whether narrative may play a part in how they communicated their experiences due to the lack of relevant research. Therefore, a narrative approach did not initially appear as an appropriate methodology.

Interpretive Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) has been proposed by Howard, Katsos, and Gibson (2019) and MacLeod (2019) as constituting an inclusive approach to researching experience in autism research, though they focus primarily on the use of interview techniques while recommending the use of creative methods when participants do not communicate verbally. Their argument rests upon the notion that researching experience through a double hermeneutic process is innately inclusive, possessing the power to alleviate the double-empathy problem (Howard et al., 2019, p. 1871) as researchers acknowledge that the findings represent their interpretation of how the participants have interpreted their experience. As the double hermeneutic requires participants to pause and reflect on what an experience meant for them, it may not have utility when eliciting accounts from

participants who communicate through vocalisations and body language, as there will be an inevitable question of whether their communication is reflective or 'in the moment'. The focus on the individual (Finlay, 2011, p. 140) does hold inclusive value, though IPA remains here, in the sense-making process, and does not look to wider contextual factors that were highlighted (Chapter 3.2) as important in the context of life conditions and autism and profound learning disability.

The book by Simmons and Watson (2014) that was discussed previously provides a detailed methodology with which to research the experiences of people with profound learning disabilities. Although I found its constructionist approach to present some issues in the context of inclusive autism research, its framework could still be applicable to those working from a constructivist perspective, though the methods would need to change accordingly. The researchers explored different interpretations of the participant, Sam, through the scope of three theoretical perspectives: behaviourism and cognitivism – two approaches common in the field of profound learning disability – along with phenomenology – primarily the theories of Merleau-Ponty (1962). Behaviourism and cognitivism are perhaps insensitive in the context of inclusive autism research due to the long history of questionable practices and theories stemming from their fields (Milton, 2012b, pp. 7-8), suggesting that at least part of the methodology may be inappropriate for research in the space of autism and profound learning disability. It may be fortunate then that Simmons (2018, pp. 125-144) has since provided a strictly phenomenological framework for exploring the social experiences of people with profound learning disabilities through the scope of intersubjectivity; however, the focus on the social experiences of its participants is too specific for a methodology that aims to uncover experiences of everyday life as there may be other dimensions of experiences more significant from the perspective of autistic people with profound learning disabilities within day services.

What is particularly valuable in Simmons' & Watson's (2014) approach is their efforts to see the complexities of Sam's world by utilising multiple methods and methodologies. Although the researchers did not acknowledge it as such, this could be considered 'bricolage' research (Rogers, 2012) in that it brought together diverse perspectives and practices in order to 'respect the complexity of meaning-making processes and the contradictions of the lived world' (Rogers, 2012, p. 4). Bricolage approaches are advocated by Brownlee-Chapman et al. (2018, p. 891) within inclusive learning disability research as they source methods and methodologies that are appropriate for specific research contexts and their related participants and researchers. In doing so, studies can incorporate methods that are suitable for diverse knowledge capacities, communicative styles, life contexts and so on, in order to 'push and disrupt other constraining, and potentially oppressive, borders in qualitative research' (Rogers, 2012, p. 14). To do this

in the context of everyday life at day services and the experiences of autistic people with profound learning disabilities, the concept of lifeworld fractions (Ashworth, 2006, 2016) will be presented in the following section, as it will argue that it provides a framework to source and introduce methods and practices that are appropriate for exploring experience as participants communicate it. This is valuable, I contend, as it addresses the third objective related to developing a methodology to explore the experiences of autistic people with profound learning disabilities: to establish ways of researching that are appropriate to their circumstances and communication.

4.10 Lifeworld as an inclusive concept

A lifeworld can be defined as ‘a person’s subjective construction of reality’ (Kraus, 2015, p. 4). It is the taken-for-granted way in which a person experiences the world - the pre-reflective unfolding of our daily existence (Finlay, 2011, p. 125). We rarely reflect on the meaning given to us in our everyday experiences, ‘they are simply lived through’ (Ashworth, 2016, p. 20). Throughout phenomenological thinking, the lifeworld is regarded as the basic structure for our being in the world though, with consideration for the aforementioned constraints of intentionality, how we access and understand it create areas of debate (Finlay, 2011, p. 126).

One way to contemplate the lifeworld is through the scope of lifeworld fractions, as conceived by Peter Ashworth (Ashworth, 2006, 2016). The fractions are eight essential elements that constitute the lifeworld. Ashworth defined these by drawing from a broad range of phenomenological theory concerned with lifeworlds, arguing that within any experience all eight fractions will be felt to greater or lesser extents. Each fraction gives meaning to a person’s lifeworld, merging with one another though each distinct in its own right (Ashworth, 2016, p. 24). If one considers how a person experiences a phenomenon from each fractal perspective, it is possible to illuminate the complexities of their lifeworld. They are there for any person in any situation, innate to human consciousness (Ashworth, 2006, p. 219). To instantiate the fractions, the following descriptions refer to a personal experience of disclosing a minor ailment (a cough) to a General Practitioner (GP):

- Selfhood – What is our experience of identity in a situation? Perhaps we experience an empowered sense of self, or in contrast, one that is lacking autonomy. When informing a GP of a cough, the self is experienced as a fraud – a timewaster. The ill self is not ill enough. One is vulnerable to judgement.
- Sociality – How do others affect how we experience a situation? What is our experience of the relationship? How do we affect each other? A GP is superior. I present my evidence to them and

they decide what I am. Their actions, appearing to listen and show consideration, affects how I experience myself - I become validated.

- Embodiment – How do we experience our bodies in a situation? Is there strength and ease of movement, or do we feel incapable? Gender, disability, age and ethnicity may be felt as they sit in the social and cultural context of the situation. The body does not conform when revealing a cough to a GP: it is too strong for the situation. Nerves take hold as one discloses.
- Spatiality – What does space mean to us in a situation? What are its related customs and practices? Does space welcome us or turn us away? The GP's office is strange and unfamiliar. The way in which the GP sits – half way towards the computer, half way towards myself – presents an ambivalence.
- Temporality – How do we experience the passing of time in a situation? In what ways does our biography confront us? Our past, present and future is felt. What temporal orders are we connected to? Time in the GP's waiting room expands out while the conversation with doctor speeds by. The GP's room presents a scene from childhood.
- Discourse – What discourses do we draw from in a situation? What are the societal and cultural contexts of the actions and expressions in a situation? Talking to a GP I draw from a discourse of illness. I exaggerate it. I act it out – it is a performance.
- Moodedness (mood as atmosphere) – The feeling that relates to the atmosphere of the situation. Not what is inside, but the general mood one senses when experiencing something. Sitting in a waiting room, one is engulfed with dread – it emanates out from its pores – escaping the situation lifts the cloud.
- Project – Our abilities to pursue the things we care for in a situation. Is a situation enabling or disabling? If the former, we may experience pride and achievement, if the latter, anger and sadness may confront us. When disclosing an ailment I wish to see this resolved – to be cared for – a considerate response from the GP presents an experience of relief. The cough is attended to but also I have not embarrassed myself through a needless doctor's appointment.

The fractions, Hodge (2008, pp. 30-31) argues, represent an inclusive (emancipatory) methodology for autism research as the researcher dedicates themselves to understanding the participants' experiences whilst relating them to their wider socio-political contexts. Phenomenological methodologies that draw from the descriptive tradition, as lifeworld fractions do, are to some extent all concerned with explicating the lived through meaning of peoples' experiences and so, in this sense,

lifeworld fractions offers no greater inclusive merit than any other descriptive methodology (Hodge (2008, p. 36) acknowledges this). The argument that the positioning of experiences within their socio-political contexts can reveal disabling barriers (Hodge, 2008, pp. 31-32) could also be extended to other phenomenological approaches – it is not part of a descriptive approach and neither is it advocated by Ashworth; it could even be argued that it is contrary to the descriptive tradition for straying from the experience as given.

What Hodge (2008, pp. 34-35) and recently, Andrews et al. (2019), highlight of inclusive value in the context of autism and learning disability research is the potential of the fractions as a tool with which to direct the interrogation of experience in a complex and open way. As Ashworth (2016, p. 21) notes, the phenomenological analyst may fall foul of the psychologist's fallacy, the assumption that their subjective position represents that of the reality of the participant's (see Ashworth, 2009), if weight is given to their personal interpretations – a risk likely exacerbated when considering the double empathy problem (Chown, 2014; Milton, 2012a). The intricacies of the experienced lifeworld in everyday circumstances may not be readily available on first consideration, yet the fractions provide a framework in which researchers and research collectives can explore the experiences of participants in a multi-faceted way that may reframe prior assumptions and bring about new interpretations. Thomas Andrews (Andrews, 2017; Andrews et al., 2019) demonstrated this applicability when interviewing parents about the developing sexualities of their related autistic children, using the fractions to support them to build on their existing understandings of their children's experiences and reimagine their situations from fresh perspectives. They prompt even those with years of experience of engaging with autistic people with learning disabilities to look more closely at how they have previously interpreted experience and in this sense, the fractions hold inclusive potential, as they can help to challenge assumptions that might have arisen in relation to the double empathy problem and inclusion phobia.

The research of Andrews et al. (2019) demonstrates the potential of lifeworld fractions for research in the space of autism and profound learning disability. However, Ashworth (2016, p. 21) presents them from a distinctly descriptive stance, therefore, it is unclear how they could be used in a study situated toward the interpretive school of phenomenology, where contextual factors are of consideration. There is evidence of their usefulness for researching when interview methods are inappropriate for participants, in this case a person with Alzheimer's (Ashworth, 2006), though there is no specific methodological approach provided. Other studies (Andrews, 2017; Ashworth, Freewood, & Macdonald, 2003; Finlay & Molano-Fisher, 2008; Greasley & Ashworth, 2007) that have adopted lifeworld fractions as a methodology, framework or analytic guide have used interviews as their primary method of

data collection, leaving little suggestion of their applicability when exploring the experiences of people with profound learning disabilities.

4.11 Lifeworld fractions and bricolage

To highlight the potential of the fractions in exploring the everyday experiences of autistic adults with profound learning disabilities in day services, it is helpful to return to the bricolage approach as described by Rogers (2012) and advocated by Brownlee-Chapman et al. (2018, p. 891) within inclusive learning disability research. As mentioned, bricolage denotes a pluralistic approach in that researchers draw from and utilise methods and methodologies that are appropriate for the research at hand. They do not bind themselves to any particular methods or approaches as they acknowledge that they may not be able to address issues that arise as research progresses; it therefore requires continued assessment, negotiation and development. For those working in inclusive research (Brownlee-Chapman et al., 2018), bricolage allows researchers and participants to contribute in ways that they choose and that are appropriate for the developing research, as it is considered that there is no one correct way to do so (Rogers, 2012, p. 4). While the fractions don't initially appear related to bricolage methodology, their grounding in a broad range of theory – phenomenology primarily, but also other areas such as discourse theory (e.g Harré & Gillett, 1994) and human geography (e.g Seamon, 1979) – means that each fraction is a signpost to further ideas, theories, methodologies and methods. Identifying fractions that are relevant to research questions and the concerns of the participants can therefore open up new methods of inquiry. In this sense, the real distinction of the fractions is that they are a clearly defined and accessible tool that supports not only ways of thinking about experience, but also ways of thinking about how to research experience. Although a phenomenological framework may not sit well in the traditional view of bricolage in that it does not necessarily give breadth to the fully diversity of methodologies – it is perhaps limiting – the fractions may however facilitate thought for concepts and approaches that are not initially considered by researchers. If this is the case, they could be considered both enabling of bricolage approaches for researchers that may not possess an in depth understanding of potential theories, methodologies and concepts, while also restricting for those that are more experienced. Working in relation to the third space and the potential diversity of research collectives, this may favour the former rather than the latter.

Bricioleur has an interesting link with arguments made by Zahavi (2019) regarding phenomenological approaches. For Zahavi (2019, p. 905), central phenomenological concepts should make a difference to the way in which 'data are obtained', that is, as a researcher learns about participants' experience of a phenomenon, methods and approaches should be used with consideration

of their relationship to phenomenological theory. There are no particular methods that are inherently correct for phenomenological research that takes this approach: it is the responsibility of the researcher to adapt through close attention to what the participants tell them and the context in which this happens, negotiating as the research progresses. The concepts that arise as significant should guide subsequent investigation with new methods being adopted where appropriate. Zahavi's phenomenological approach is to some extent then, similar to that of bricolage.

The crux of Zahavi's argument is that 'to conduct phenomenologically informed qualitative research is not merely a question of being open-minded and interested in first-person experience. It is very much also about adopting and employing a comprehensive theoretical framework concerning the subject's relation to himself or herself, to the world, and to others' (Zahavi, 2019, p. 906). Zahavi's issue is that methodologies such as Interpretive Phenomenological Analysis (Smith et al., 2009) focus merely on what an experience is like for a person – what he terms phenomenality (Zahavi, 2019, p. 906) – while disregarding the philosophy that constitutes phenomenology. This issue is similarly raised by Dahlberg and Dahlberg (2019) who understand IPA to be a type of content analysis in which the meaning of experience is lost. Such an approach is certainly qualitative, but for Zahavi (2019, p. 906), cannot be called phenomenological. Although Smith (Smith, 2018; Smith et al., 2009, p. 32) has argued that IPA is underpinned though not constrained by phenomenological works, this is not of concern for the current discussion as IPA was earlier argued to be unsuitable for research with people with profound learning disabilities. What is salient is that the fractions maintain their applicability in the context of the phenomenological approach that Zahavi puts forward. Phenomenological theory is dense and difficult to unpack, yet the fractions work on a number of levels, appearing initially as accessible concepts that are relatable to everyday circumstances, while containing within them the complexity and depth that makes up the experiential lifeworld. This makes them adaptable to different research contexts, offering a framework to explore experience with research collectives of differing circumstances and introducing methods and approaches relevant to on-going findings. To use the fractions on the surface level, as described by Ashworth (2006, 2016), presents an accessible method to guide a study concerned with experience and that may be described by Zahavi as phenomenality, see for example the aforementioned research of Thomas Andrews (Andrews, 2017; Andrews et al., 2019). However, researchers can also make use of the phenomenological theory that Ashworth drew from to define the fractions (Ashworth details these theories and theorists in 2006 and 2016), and in doing so interrogate experience through key phenomenological concepts in a manner that is closer to what Zahavi terms 'phenomenologically informed research' (p.906).

In a series of seminars in which autistic and non-autistic academics, community members and social care professionals contributed ideas on how to create inclusive autism research practice (Fletcher-Watson et al., 2019, p. 948), it was identified that research design is never intrinsically inclusive at conception as it requires ‘continued consultation’ to ensure methods remain appropriate for the autistic people involved. Inclusive design in both autism (Fletcher-Watson et al., 2019) and learning disability (Brownlee-Chapman et al., 2018; Seale et al., 2015) fields therefore share commonalities with Zahavi’s concept of phenomenological research in that they all require researchers to work with participants to identify and utilise methods that are appropriate to their life circumstances and their experiences of phenomena. Inclusive phenomenological research should not seek to define ways of researching with autistic people with profound learning disabilities based on preconceptions concerning how they communicate or the ways in which they live their lives, it instead requires a dialogue between participant and researcher in order to develop methods relevant to the relationship between their everyday experiences and the fundamental concepts of any human consciousness. ‘The researcher... has to gain the person’s trust and inspire confidence; they also need to deserve this trust’ (Finlay, 2011, p. 192). One such way to do this is to ‘think phenomenologically while doing phenomenology’ (Berndtsson et al., 2007), which I contend can, when used with lifeworld fractions, address the final two objectives of this methodological development. That is: to explicate phenomena through the experiences of autistic people with profound learning disabilities; and, to enable practical research processes in which autistic people with profound learning disabilities can meaningfully participate, and, where possible, shape according to their perspectives, such as in the choice of study methods and their focus.

4.12 Thinking phenomenologically while doing phenomenology

The nature of lifeworld conditions means that researchers can to some extent share in the lifeworlds of others – a position that regards human beings as innately able to understand and interpret (Berndtsson et al., 2007, p. 261; Heidegger, 1996) - though this requires a research process that is appropriate to the uniqueness of the phenomena under study. One way to achieve this is for researchers to ‘think phenomenologically while doing phenomenology’ (Berndtsson et al., 2007, p. 256) - to consider and respond to lifeworld ontology through the way it appears in the natural attitude: the taken for granted reality of everyday life (Muzzetto, 2015, p. 247). Faced with the full complexity of the lifeworld and that of the phenomenon under study, the researcher is forced to make methodological decisions in an attempt to capture the phenomenon as close as possible to that as experienced (Berndtsson et al., 2007, p. 261). Berndtsson et al. (2007, pp. 262-263) recommend that researchers begin by examining relevant literature

before observing and engaging with participants in their everyday environments – a kind of ethnographic method in which the researcher learns about their participants – what they do, how they do it, who do they do it with, what they use to do it, how they talk about it. Throughout, the researcher should:

- Maintain a broad and reflective stance on their methodological choices.
- Remain open to the unique ways the phenomena are experienced by the individual.
- Discuss pre-understandings and how they influence the process.
- Consider the surrounding context – the participants' life situations.

Put simply, the researcher is attempting to understand some of the taken for granted ways in which the phenomenon is experienced so that they can explore this from a phenomenological perspective – through an engagement with philosophical works and theories – and subsequently adopt research methods that can explicate 'phenomena in a 'lifeworldly' open, often complex and multifaceted perspective' (Berndtsson et al., 2007, p. 261). I regard this approach as congruent with the ideas of Kraus (2015) whose epistemological constructivism was key to the development of this methodology, it being that Berndtsson et al. (2007) are similarly suggesting that when people share the life conditions of day-to-day life, they also share in each other's lifeworlds, and so exists a relationship between the lifeworld and its subjective construction processes, and the life conditions that one shares with others in the context of an ontological reality (Kraus, 2015, p. 5).

One example provided by Berndtsson et al. (2007, p. 261) is a study that investigated how teachers utilise students' experiences within a prison classroom (Claesson, 2002). Through initial observations, Claesson (2002) found significance in the ways in which teachers related students' physical behaviour and mannerisms to their experiences outside of prison. It was apparent that the phenomenological concept of directed awareness (Merleau-Ponty, 1962) was central to lifeworld ontology within this context – the taken for granted ways in which the teacher directed their attention toward students' bodily actions. Subsequently, the researcher chose to further observe the classroom, taking notes and making drawings of body shapes during interactions, alongside traditional interview and discussion methods. The phenomenon as experienced by the participants shaped the research process.

A longitudinal study design is necessary in facilitating the process of thinking phenomenologically while doing phenomenology as a researcher must commit time to orientating their perspective to the taken-for-granted nature of everyday life of participants (Berndtsson et al., 2007, pp. 261 - 262). This marks further similarities between a lifeworld approach and those advocated for research with people with profound learning disabilities (Goode, 1994; Mietola et al., 2017; Simmons & Watson, 2014b, p. 149) in that the experiences of participants can only come to be understood by spending time with them in

their day-to-day contexts. This is termed 'being-with' by Morris (2003, p. 345) while researching the experiences of children with 'significant cognitive impairments' and involves observing and joining in with the activities and routines of participants in order to learn from them in the moment and in relation to the surrounding environmental contexts. A bricolage approach is beneficial here as the idiosyncratic communication of participants may require methods to be adapted in accordance with different circumstances, for example the communication of a participant in the study by Morris (2003, p. 345) was markedly different across school settings and thus their methods changed to suit the situation. Although being-with is a method of data collection, it is significant for the methodological direction of a lifeworld study as it is the resulting knowledge and understanding that must shape the study focus and the way that the research is carried out. Berndtsson (2001) for example, found that the everyday experiences of people who had developed visual impairments was a pedagogical process, though this focus was only realised after a period of the researcher 'being-with' participants in their day-to-day circumstances, with the subsequent introduction of theory (Merleau-Ponty, 1962) and methods (life story interviews, participatory observation and diaries) relevant to exploring this more acutely.

The lifeworld approach put forward by Berndtsson et al. (2007) rests on the assumption that researchers possess an in-depth knowledge of phenomenological theory that they can relate to research contexts after an initial period of data collection. They do not employ any specific framework and neither do they suggest any specific ways that researchers should connect their initial findings to areas of lifeworld ontology. The featured researchers (Berndtsson, 2001; Claesson, 2002; Öhlen, 2003) who employ the approach are all well versed in phenomenological theory as they work in a research community developed around phenomenological practice (Berndtsson et al., 2007, p. 258). Although there are obvious benefits in having a broad and knowledgeable understanding of phenomenological theory in order to conduct phenomenological research, researchers will inevitably differ depending on their backgrounds and many will not have had the same opportunities to familiarise themselves to the extent of Berndtsson et al. (2007). This may only be exacerbated by the complex and difficult to access writing so often found in phenomenological works (Andrews et al., 2019, p. 2; Dahlberg & Dahlberg, 2019; Van Manen, 2007, p. 13). To think phenomenologically while doing phenomenology in the manner described by Berndtsson et al. (2007) is thus inaccessible to any researcher without many years of study dedicated to phenomenology; however, this can be overcome through the use of lifeworld fractions as a guiding tool. Ashworth (2016) has defined the fractions by drawing from the works of well-established phenomenologists such as Husserl (1960), Heidegger (1962) and Merleau-Ponty (1962) and in doing so, as Dahlberg and Dahlberg (2019, p. 5) note, provides a starting point to understanding how phenomenological theory may relate to empirical

research. Initially, a researcher only requires an understanding of the fractions at the surface level, as described previously, though as fractions emerge as significant to participants' experiences of a phenomenon, the underlying theory can be investigated more closely. In under researched areas in which a researcher has little understanding of how potential participants may experience a phenomenon, the fractions provide a broad perspective that can be narrowed down in relation to on-going findings and the most prominent fractions. A bricolage approach can follow as methods need to be relevant to the developing phenomenological focus, and this can be aided through reference to research that has previously utilised the pertinent theory. For instance, if sociality arose as significant to the everyday experiences of autistic people in day services, the aforementioned approach by Simmons (2018, pp. 125-144), which utilises sociality theory of Szanto and Moran (2015), Merleau-Ponty (1962) and others, could suggest ways in which to develop the on-going study.

Ideally, when investigating the lifeworlds of autistic people with profound learning disabilities through the understandings of a research collective, a researcher should attempt to facilitate methods that can help to equalise the disparity of knowledge; that is, researchers possess an understanding of the complexities of phenomenology that many in a collective will not. In other words, an inclusive approach to lifeworlds means that it would be beneficial if co-researchers could also think phenomenologically whilst doing phenomenology. To do this would require a study design with considerable input from a research collective, such as involving them in parts of the analysis, discussions on aspects of phenomenological theory and how this could relate to the participants, or designing methods with co-researchers that could explicate the participants' experiences of the phenomenon as they understood it. This is not an impossible task as demonstrated by two inclusive research projects (Brownlee-Chapman et al., 2018; Liddiard et al., 2019). 'Living Life To The Fullest' (Liddiard et al., 2019) explores the lives of children and young people with life-limiting and life-impairing conditions and is co-produced – from conception to publication – with people with relevant lived experience. 'The Living Archive of Learning Disability' (Brownlee-Chapman et al., 2018) involves work from researchers with and without learning disabilities to facilitate the design and development of an archive that documents the histories of people with learning disabilities, and this has resulted in innovative concepts such as accessible methods for conducting literature reviews. Although it is argued that lifeworld fractions could hold some potential in facilitating such inclusive practice when researching experience, this will be dependent on parameters such as research funding, time constraints, and the extent to which members of the research collective wish to be included.

4.13 A summary of the methodological contribution

This chapter has developed and presented a novel methodological approach for researching the experiences of autistic people with profound learning disabilities. Drawing from Ashworth (2016) and Berndtsson et al. (2007), this approach can be termed ‘using lifeworld fractions to think phenomenologically while doing phenomenology’. There were five objectives of this methodological development, each that were considered and addressed in turn over the course of the chapter. The first was to establish ethically sensitive ways of developing research for autistic people with profound learning disabilities. The earlier literature review had highlighted epistemic issues in separating the terms of autism and severe/profound learning disability, in relation to people with complex needs, and so ethical consideration was given to this issue. It was argued that the separation of the terms only serves to further the marginalised position of people with complex needs in academic and political life, as their voices are not adequately represented within broader discourses around autism and learning disability. To address this, the phenomenological concept of life-conditions (Kraus, 2015) was drawn from, to recognise the shared circumstances of people with complex needs related to the terms autism, severe learning disability and profound learning disability. This perspective provided a basis with which to establish an academic space of ‘autism and profound learning disability’: a space in which to develop methodologies and conduct research that respond to the voices, values and views of related people.

The second objective of the methodological development was to establish ways of researching that are sensitive to the values and perspectives of autistic people with profound learning disabilities and their related communities. This was done through consideration of the third space of inclusive research, as drawn from by researchers concerned with learning disability (Seale et al., 2015) and autism (Andrews et al., 2019; Bertilsdotter Rosqvist et al., 2019). Specifically considered was a way of researching that involves the social and support circles of autistic people with profound learning disabilities, termed research collectives, with relevance to two concepts: the double empathy problem (Milton, 2012a) and inclusion phobia (Goodey, 2015). Suggested as an ethical risk was the power dynamic apparent when groups of people that do not identify as autistic, or with a learning disability, interpret the experiences of autistic people with profound learning disabilities. Constructivism was argued to be an approach to knowledge construction that could minimise this risk, and consequently, it formed the epistemological basis for the methodology.

The third objective was for the methodological approach to enable research into experience in ways that are sensitive and appropriate to the communicative styles, lifestyles and circumstances of autistic people with profound learning disabilities. It was contended that lifeworld fractions (Ashworth,

2016) and bricolage (Rogers, 2012) can aid researchers to develop research in ways that are relevant to the circumstances and perspectives of participants, through a framework that points to methods and theories relevant to their experiences. Such an approach is adaptable to the diverse communication of autistic people with profound learning disabilities, as it does not require any particular method or way of collecting evidence of their experiences. A further contention was that the framework of the fractions holds inclusive value, as it enables researchers, and possible research collectives, to challenge assumptions they may hold relating to the experiences of autistic people with profound learning disabilities. This is also supported by the accessible nature of the fractions, holding potential for use with research collectives of different skills and abilities.

Finally, by conceiving of lifeworld fractions as a tool to guide the process of thinking phenomenologically while doing phenomenology (Berndtsson et al., 2007), the last two objectives of the methodological development were addressed. First, this approach provides a way to explore phenomena through the experiences of autistic people with profound learning disabilities, as it prompts the researcher to adapt their ways of researching according to what they learn of participants' experiences and relevant phenomenological theory. Understandings of the study phenomenon thus becomes contextualised, through the everyday, taken-for-granted ways in which it is experienced by participants, and in relation to its surrounding environments and circumstances. In this way, the approach is appropriate for use in the space of autism and profound learning disability, as it is congruous with the way in which the space was conceived: through the interrelated nature of lifeworlds and life-conditions (Kraus, 2015). Second, the approach prompts practical research processes in which autistic people with profound learning disabilities have meaningful participation, as it requires the researcher to learn of their experiences in the context of their everyday lives, through the ways participants communicate their experiences. The researcher must commit themselves to adapting the research, its methods and focus, through the lifeworld perspectives of participants, therefore a study design can, to greater or lesser extents, be shaped by autistic people with profound learning disabilities. This last objective, relating to meaningful participation and the practical outcomes of the methodology, is explored in more detail through a discussion chapter, written after the empirical investigation into day service culture, and with reflection on the participation of Ben, an autistic adult with profound learning disabilities.

In developing the methodology detailed above, it was possible to plan and conduct a study that explored the phenomenon of everyday life within a day service from the perspectives of autistic adults with profound learning disabilities. This study and its related methods, those that developed through

using lifeworld fractions to think phenomenologically while doing phenomenology, are thus detailed in the following chapter.

Chapter Five – Methods

This chapter presents the practical processes involved in conducting a study that explored day service culture through the everyday experiences of autistic adults with profound learning disabilities. It begins by detailing the process of seeking a favourable ethical opinion in a study that sought to include people who were considered to not have capacity to consent to participate. This includes references to the potential benefits and risks to participating, as well as methods and strategies that were to be implemented to create a safe research environments for those involved. Subsequently, the process of gaining access to a research site is outlined and this is followed by a description of the recruitment process.

As the methodology is novel in conception, involving a cyclical process of fieldwork, analysis, fieldwork, analysis and so on, with evolving methods and theoretical perspectives, this chapter details the processes. This includes discussing and providing justification for the methods chosen to begin the study, as well as describing subsequent stages of analysis as these findings consequently guided further periods of fieldwork and the methods involved. As such, some data will crop up to illustrate the process of ‘thinking phenomenologically while doing phenomenology’, though it is important to emphasise that this was not, and is not, the final analysis – this will be presented in subsequent chapters. Having said this, the chapter concludes with details of the final analytic methods.

5.1 *Negotiating a favourable ethical opinion*

The ethics process began in July 2018 and followed two required routes: an application to The Open University Human Research Ethics Committee (HREC) and another to a regional (Coventry and Warwickshire) Social Care Research Ethics Committee (SCREC) through the online Integrated Research Application System (IRAS). Both asked for:

- Justification of the research.
- A description of the methodology and the intended methods: data collection and analysis.
- The participant selection criteria.
- The planned recruitment procedures including gaining consent of participants.
- Information and consent forms for participants.

- A schedule including locations of fieldwork and planned time commitments for researcher and participants.
- Details of intended data handling and how this corresponds to data protection law.
- An assessment of the risk of harm to participants and how this will be minimised.
- The intended ways the research will be disseminated.
- The potential benefits and knowledge transfer of the study.

As I planned to involve people in the study that could be considered to lack capacity to consent to participate, and that historically could be considered to have experienced hardship and marginalisation as a result of research (Mietola et al., 2017; Silberman, 2015), I provided as much detail to the RECs so that they could understand the how the research would meaningfully involve the intended participants whilst minimising any potential risks. These methods will be discussed in the following sections, alongside their potential benefits and risks. By February 2019, both ethics committees had provided a favourable ethical opinion for the research to proceed. All aspects of the fieldwork described in this chapter were covered by the ethical approval granted by both RECs.

5.2 *Use of language henceforth*

Although the term inhabitant will be used through the subsequent chapters, it was decided upon after data collection and as such, the data features a number of ways to identify inhabitants as well as other people, particularly support workers. To make it clear as to whom I am referring to, here I will define any terms that I used in data collection and also state how people will be referred to henceforth.

- In fieldnotes, inhabitants are referred to as service users. I often assigned them pseudonyms but used service user to clarify that they were not a member of staff. In the latter fieldmaps method, 'person' is generally used to identify inhabitants though there is also an occasional use of 'SU' when paper space was lacking. Ben, the participant whose experiences are the subject of this thesis, was always referred to with this pseudonym. As stated, these people will now be referred to as 'inhabitants'.
- Across data collection, support workers were referred to as either staff, support workers, support staff or SWs. In fieldnotes, I also assigned pseudonyms to those that regularly worked with Ben,

clarifying in the notes that they were a support worker. For clarity, I will only use support worker(s) when referring to staff that on a day-to-day basis support inhabitants as their primary roles.

- At times senior members of staff are apparent in the data – referred to as senior support workers, senior staff or managers – depending on their position within the organisation. In future writing, I will make clear who I am referring to using ‘senior support worker(s)’ or ‘manager(s)’.
- If I am referring to senior support workers, managers and support workers in one group, I will use ‘service staff’.
- If I am referring to support workers and inhabitants in one group, I will use ‘the Hall’s people’.
- On most days of fieldwork, agency support workers were working at the service. These are support workers that the service temporarily hires from an agency company to cover staff shortages or illness – some I only saw once while others where there regularly. In fieldnotes and fieldmaps, they are either referred to as agency staff, agency, or agency support workers. It is important to differentiate them from the support workers employed by the service as they appeared to have different roles in the context of day-to-day life. Henceforth they will be referred to as ‘agency support worker(s)’.
- Parents of inhabitants would occasionally be seen within the service and there is evidence of this in fieldnotes and fieldmaps – ‘parent(s)’ seems a sufficient term to continue with.

5.3 Establishing a research site, recruitment and seeking consent

After receiving favourable ethical opinions to conduct the research, I contacted an autism service as provided through a local authority in England. I first engaged with them via email and telephone, providing the study proposal and confirmation of the favourable ethical opinion. As this phenomenological approach was novel in its conception, there were no clear guidelines as to the extent to which I should recruit participants. Its grounding in the interpretive tradition meant that there was a need to examine the study context as well as the phenomenon of everyday life from the lifeworld perspective of the participants. The aim in a lifeworld approach is to understand and elucidate, as close as possible, the multiple facets of meaning that reside in the experience of a particular phenomenon (Ashworth, 2016, p. 20), and so while listening to the accounts of multiple participants could reveal patterns of experience in relation to everyday life at the day service, spreading data collection could also dilute the quality and depth of accounts retrieved. I decided to draw from examples of other PhD studies in which researchers worked with people who communicate through vocalisations and body language - Simmons and Watson

(2014b), Gaudion (2015) and McCormack (2017) – and made an assumption that it could be possible to collect accounts of three participants that would be rich enough to explicate their lifeworld perspectives, while also affording me time to explore the phenomenon of everyday life within the context of the day service. Another intention was to form a research collective with each participant: to recruit a support worker co-researcher, and a family member co-researcher. This was part of the methodological development that aimed to draw from the knowledge and understanding that develops between autistic people with profound learning disabilities and those they are close to (Chapter 3.3). The methods used with and by the researcher collective are given full detail from section 4.7 onwards.

Purposive sampling was used as a recruitment method, as it enabled me to recruit participants ‘most likely to have in-depth knowledge and experience of the phenomenon being studied’ (Campbell et al., 2020, p. 656), which in this case, was everyday life within a day service. Specifically, I sought to focus on the knowledge and experience of autistic people with profound learning disabilities, which had been established in the literature review as being an unclear identifying term, but that may include autistic people with severe or profound learning disabilities, and who are considered to have complex needs. This literature review was to some degree, a way to overcome the risk of research bias apparent in purposive sampling (Robinson, 2014), as it led to a considered inclusion criteria that described who the research sought to recruit. Regarding the participant that was recruited, descriptions of his circumstances, needs and day-to-day activities are provided, alongside the in depth account of his experiences at the day service (Chapter Six, Part One), which provides a way of locating him within ‘autism and profound learning disability’, that being that his day-to-day skills and understanding suggested a person that could be considered autistic with severe learning disabilities.

Recruitment took place at an autism day service, which I was aware of as supporting people with complex needs. This could be considered a weakness of the recruitment approach, in that the culture of the specific day service may not relate closely to that of others, where inhabitants have less complex needs, or where the service has a focus on learning disabilities as opposed to autism. That being said, cultures are by their nature, unique to day service organisations, and thus even two service organisations with very similar purposes may have quite different cultures. Where there would be similarities though, are in the *ways* in which autistic people with profound learning disabilities contribute to and experience culture, which is what this study aimed to understand. The purposive approach was therefore appropriate, serving a key purpose to increase the likelihood that I would be able to learn of the experiences and perspectives of autistic people with profound learning disabilities, in relation to the day service cultures that they are part of.

The selection criteria for autistic participants with profound learning disabilities were people who:

- Had a diagnosis of autism, and either a diagnosis of severe or profound learning disabilities or 'severe' autism.
- Communicate primarily through vocalisations and body language.
- Attend a day support service Monday-Friday.
- Have at least one support worker allocated to support them throughout the day (this corresponds to the term 'complex needs').

The selection criteria for support worker co-researchers were people who:

- Supports one of the above participants at least once a week.
- Has worked at the service for three months or more.

The selection criteria for family member co-researchers were people who:

- Were related to the autistic participants with profound learning disabilities.
- Were adults.
- Were in regular contact with the service.

To comply with the Mental Capacity Act 2005, the autistic participants' capacity to agree to be involved was assessed using the two-stage framework in the Mental Capacity Code of Practice (DCA, 2008, p. 41). As Boahen (pp. 378, 2005) comments, the Mental Capacity Act 2005 is underpinned by five principles, the first of which is the presumption of capacity. If there is doubt in regards to the participants' capacity to consent to the research, this must be determined through an accessible assessment. In line with this and the approved ethical framework, service management assessed whether the potential participants had capacity to consent to the research using an accessible information form. As they were considered to lack capacity, their family members were contacted via post with an invitation letter and information sheet that asked them to contact the researcher if they thought that their family relation may be interested in participating in the research, as well as involving themselves as co-researchers.

Two of eight families responded and after email and phone conversations with both, one thought that their son would want to be involved in the research. To provide anonymity, this person was given the pseudonym Ben. His mother was nominated to act as a safeguard to monitor his wellbeing through the research and to provide any information or advice prior to the fieldwork beginning, though it was agreed

that Ben's support workers would be in the best position to do this. This was also discussed with senior staff at the day service. Consent forms agreeing to Ben's participation and their own as co-researchers were signed by Ben's mother and step-father. The parents that decided that their son would not want to be involved in the research did so after detailed discussions on the study methods and his current life circumstances. This is evidence of the study's ethical integrity in that it provided a means for which to assess the risks and benefits of the research for each potential participant, considering what the research may mean for them and how the participatory methods may be experienced in practice.

Through the study information sheets and prior conversations, support workers were asked to inform myself, senior staff or the study supervisors if at any point they felt that Ben no longer wanted the research to continue. During fieldwork, Ben was considered to assent to the research – a position that recognises his abilities to choose to participate or not by paying close attention to his communication throughout the research (Haines, 2017, p. 226). Individual methods and environments could be assessed by allowing Ben to speak for himself - any signs of distress or actions that would indicate that he did not want the interaction to continue would be understood as such and acted on. It was vital to respect Ben's requests, but also not to assume that his communication was indicative of the research as a whole: just like participants of any research, it may be that he was not feeling well that particular day, or that the method was encroaching on his activity. As such, assent primarily required consideration and input from his support workers and myself who discussed any potential issues as they arose. Many support workers informed me that Ben preferred 'minimal communication' – that is, to restrict verbal communication toward him – and this was echoed in his communication plan; so when meeting him each morning, I followed the way he would acknowledge people, exchanging a nod or holding my hand out for a gentle high five. The rest of the time I remained a passive observer unless Ben engaged with me, such as when he looked through my field notes book. Management also provided ongoing information and advice - such as when Ben had been upset at home the previous evening – enabling an avenue in which to consider wider issues that may impact Ben. Ultimately, the research methods did not appear to have any negative effects on Ben and he was entirely accepting of the process, seemingly interested in my ongoing presence and activity.

While the primary focus of the study was to explore Ben's experiences at the day service, I also sought to collect data on everyday life more broadly, including the actions and interactions of staff and other inhabitants. Regarding staff, information about the research was circulated via email, as well as through a number of information sheets pinned up around the day service, which detailed what the research was about, who they could contact to find out more (senior management, myself, my supervisors

and an independent academic at the OU), and how they could opt out from being involved in the research. Some staff asked me questions about the research, such as what its purpose was, what I was observing, and what it might result in, and, though no one asked to be excluded entirely from the study, one support worker did ask not to be observed when working closely with Ben, as they had not worked with him before.

Regarding other inhabitants, information sheets and accessible information sheets were distributed within the day service, as well as being pinned up around the building, again detailing information about the research, what it was about, what I was doing, who they could ask about it, and how they could opt out. Similarly to staff's enquiries, I spoke to a number of inhabitants who had questions, such as how long I was going to be there and what I was doing. Within the day service, as in the case of Ben, there were some inhabitants that could be considered to lack capacity to consent to participate in the study. As agreed by the SCREC, to manage consent and assent for these people, I met with senior management at the day service prior to fieldwork beginning to discuss the issue. As part of an inhabitant joining the service, management conduct capacity assessments in order to establish whether they can be considered to have the capacity to consent to having information about themselves communicated outside of the service, such as pictures of them on the service's social media, and stories about them in newsletters. For those that are not considered to have capacity to make that choice, management discuss with nominated guardians (usually parents) as to whether they think the inhabitant would be happy for this to happen, including their involvement in any research that may happen at the service, and this information is subsequently kept on file. During this meeting I was informed of two inhabitants that I did not have permission to include in the research, though I did not at any point see them during fieldwork (they were primarily supported on an outreach basis). There were also a number of inhabitants who did have capacity to make that decision, and who, when joining the service, had communicated to management that they did not want to have information about themselves included in social media or research outputs, though again I did not encounter these people during fieldwork. Managing inhabitants' assent during fieldwork happened similarly to how I worked with Ben, in that I paid close attention to communication that may indicate that I, or the research, was causing distress, or that my presence was intruding on their activities or spaces. I also listened and responded to support workers advice and instructions, such as moving where I was sitting to make space for arriving inhabitants, or ensuring my communication was not overly loud or complicated.

To recruit a support worker co-researcher, senior staff provided information sheets to Ben's support workers and asked them if they would be interest in participating. They subsequently arranged a

meeting at which I discussed the research and data collection methods with one support worker. They consented to be a co-researcher by signing a consent form. I provided them a notebook with which to fill out fieldnotes and it was agreed that they would do this once a week, where possible. In order to give them a sense of the fieldnotes method, I provided examples as taken by Ben Simmons when conducting similar research (Simmons & Watson, 2014b, pp. 155-156). Although Ben's parents had also consented to become co-researchers and contribute archive material relating to Ben's experiences at day support services, they struggled to locate any and this small part of the study was omitted.

5.4 The background of Ben and the day service

Ben was 27 years of age at the time of the study. In 2011, he made the transition from school, moving to sharing his time between two day support services. Shortly after, he also moved out of his mother's home to a house share at which another service provided support workers. This unfortunately was not a good fit for Ben and made worse when the service took over his day support. Once it was recognised that Ben was unhappy with these circumstances, he returned to day service life, again sharing his time between two services, and also made a move to another house share, where he lives today with two people who he has developed friendships with. These three all communicate in similar ways – through vocalisations, direction and body language – and are provided support when at home.

On Mondays, Tuesdays and Wednesdays between 9 a.m. – 3 p.m. (approximately), Ben attends the day service at which this study is based. While here, Ben has a busy schedule that he likes to stick to, pursuing a particular plan for each day of the week that includes hobbies and interests both in and out of the day service building such as the cinema, art and the gym. If this schedule is diverted from, perhaps the restaurant that he goes to on Wednesdays is closed, or the particular treadmill he uses at the gym is taken, it can cause Ben alarm and upset. However, the majority of the time, Ben is very calm and pleasant company, showing interest in the world happening around him through his keen and patient observations. A support worker accompanies him for the duration, primarily assisting where social interaction is necessary such as at receptions or on buses, though Ben knows his day-to-day plans inside out and often leads the way. Throughout the fieldwork, the regularity of Ben's support workers fluctuated though one did have a consistent spot with him that, according to them, had been so for over a year.

Ben was entirely welcoming when we met, nodding and providing me with a small high five. I had read his support file prior to this – a requirement of the ethics process to make me aware of any risks that I may pose in Ben's day-to-day pursuits – though, in contrast to other researchers working with people

who communicate similarly to Ben (e.g. Boahen, 2013; Simmons & Watson, 2014b), I did not seek further detail from support workers or parents in regard to how to interpret his communications, or aspects of day-to-day life to look out for. This was an attempt to meet Ben at his level, not as how others knew him, but as how he introduced himself to me. Of course, support workers told me their takes on certain aspects of Ben's life, or particular situations he had been involved in, and this was recorded in order to provide a reflective and critical view on my own perspective. As Ben leads such a structured life at the day service, I quickly became accustomed to where he would be heading and what he would be doing, finding my own ways to share in this such as joining him on the exercise bikes at the gym.

Ben shares this day service with many other people - at the start of each fieldwork day, I regularly observed between twenty to thirty inhabitants and support workers occupying or passing through the main room, 'The Hall'. The service is a local charity that provides support to autistic adults (aged 18+) with different support needs through two day services, outreach work and home support. Although they try to keep a consistent schedule for support workers - I generally saw the same support workers at Ben's particular day service - they are moved between areas due to illnesses or shortages when necessary. Inhabitants have their own individual schedules that they develop with the service, so while the service building does provide amenities such as a kitchen for cooking and baking, a computer, sensory and art room and a small garden, some inhabitants choose to pursue the interests elsewhere, using the service building only as meeting space. For many others though, the building is the hub in which they spend the majority of their day-to-day lives, sharing its busy space alongside one another's occupations and activities.

5.5 Consideration for further participants

As I will make clear in the following sections, I initially recruited one person, Ben, and though I planned to recruit further, it became apparent as the research progressed that additional participants would hinder my ability to gather and analyse the data required to explore the full complexity of their individual lifeworlds. In both inclusive and phenomenological approaches, 'individuals need to feel positively involved, and this means that a relationship has to be developed with them' (Finlay, 2011, p. 192); that is, in order for experience to reveal itself to the researcher, the participants must be in a position to share it and the researcher must be in a position to attend to it. For Ben to share his experiences, I realised that I needed to devote far greater periods of time to understanding his perspective of everyday life through the fieldwork process. This was not just a case of spending time with Ben, learning of his experiences

through his communicative style and the situations that I was sharing with him, but also to understanding these moments through the phenomenological approach that I was committed to, for it was this process, I argue, that could enable me to attend to his experience of everyday life.

Once I had begun to attune myself to his experiences – to share in Ben’s lifeworld as Berndtsson et al. (2007, pp. 262-263) suggest as necessary of lifeworld researchers – I was in a position to use this perspective to focus the investigation toward the wider phenomenon of everyday life at the service. If I had pursued further participants, I would have been changing the research approach to that of the purely descriptive school of phenomenology as I would have been unable to explore the contextual basis of their lifeworlds due to time constraints, and instead the focus would have remained exclusively on their individual experiences. I am not arguing that this does not have value, but that this approach would not have allowed me to explore the broader culture of the day service: a key aim of the study. As I will detail, learning of Ben’s experiences enabled me to introduce methods to explore the wider context of everyday life at the day service in a manner that was faithful to his lifeworld perspective.

5.6 A former connection with the day service

I previously worked for the autism service in a paid capacity as a support worker though this was over two years prior to contacting them in regards to the research. This role was predominantly an outreach position (supporting people in local areas), though I had met Ben and, as far as my memory serves me correct, worked with him for an afternoon. There were both benefits and drawbacks to the study in me knowing the service and Ben, and vice versa:

- Changes to routines or unexpected circumstances can cause increased anxiety or stress for autistic adults with profound learning disabilities and having a prior relationship with a participant is one way to reduce this risk; in these cases, both the participants and the researcher have a clearer understanding of each other’s communication making it easier to interact in a way that suits the participants. This is not to say that a prior relationship is vital to the autistic participants with profound learning disabilities, as this is a group of people who regularly meet and engage with new people as they access busy service environments with high staff turnovers. However, a prior relationship can alleviate the amount of pre-fieldwork preparation between the service, family member(s) and researcher in which to establish appropriate ways for the researcher to interact with the participants. For example, in an early meeting with a service manager, they

communicated that they were happy with me researching with Ben as they thought, based on their previous knowledge of me, that I could engage with him in an appropriate manner.

- Day services for autistic adults can be busy, hectic environments that are accessed by many people with diverse backgrounds, characteristics and needs. A prior knowledge of a day service reduces the risk that a researcher acts inappropriately or intrudes on the personal space or daily activities of inhabitants. An understanding of the environment within an autism day service is essential as autistic people may rely on specific sensory surroundings that could include light and sound levels, positioning or proximity of people, or particular ways for people to dress. Furthermore, there is the possibility that some inhabitants may engage with the researcher whilst requiring particular methods of communication in response, such as one word answers or an absence of eye contact. Prior to starting fieldwork, I was aware of a number of inhabitants who enjoyed or required specific modes of engagement or communication, though I only encountered one during my research: a person who expects sayings to be repeated back to him, as opposed to responded to.
- The phenomenological approach, involving spending a large amount of time within the day service observing Ben as well as support staff, could worry or cause anxiety for staff if they feel their practice is under evaluation from an outside source. This may be detrimental to a study where the aim is to observe and gain an understanding of people's natural, day-to-day experiences. Researching at a day service at which I previously worked reduced the risk that staff would feel anxious about my presence as they could relate to my role as a previous support worker. Evidence of this was communicated during fieldwork as two support workers told me they felt that they would not feel comfortable during observations if they were not aware of my history (fieldnotes, 10th April). The benefits are twofold: there is less risk of staff feeling intruded by the researcher's presence and, subsequently, the findings may produce an account of the service that more closely reflects its normal routines. The risk that my previous role would prompt staff to ask me to carry out support worker tasks - such as supporting an inhabitant whilst the staff member had a cigarette, or asking for input within meetings – was minimised through: an information sheet explaining my role that was given to the staff that work that worked with Ben, an information sheet (with photo of myself) explaining my role that went on the walls of the day service, and communication to the support staff team from service management prior to the fieldwork.

- In contrast to the above benefits, Boahen (2013, pp. 92 - 96) draws attention to the possibility of a researcher's biography assuming prominence within the research process. By this, one refers to the way in which my past experiences at the day service, my understanding of its inner workings and my familiarity with its related people could hinder the effort that I afforded to the research and its methods. A risk existed that I would not seek new understandings through methodological rigour but rely on what I thought I already knew. It may be that I did not enquire further with participants when unsure of their motives, or that I focused on particular areas of service life while ignoring others. This risk is inherent when a researcher works from an insider perspective though I attempted to balance it through reflective and reflexive note taking throughout fieldwork.

5.7 Potential benefits and risks

Balancing the potential risks and benefits of participating in the study was important for its ethical integrity and involved consideration of the roles of the participants, co-researchers, myself and any others that I might encounter during fieldwork. As Boxall and Ralph (2011) note, any ethics committee will expect an explicit exploration of how risks will be minimised, and the potential benefits for those involved. This meant that, prior to receiving a favourable ethical opinion, I had to anticipate potential risks without first knowing who the study participants were or where it was taking place (I had planned the location of the research though at this stage had not received confirmation). One is forced to make generalised statements about the risks of working with people with a particular diagnosis, despite being unaware whether they are relevant to the eventual participants. For example, I suggested that the autistic participants may experience anxiety when meeting new people, so I planned to talk to staff about ways that I could reduce this impact and this might include using social stories or engaging with the participants in particular ways, such as with no eye contact or using minimal verbal communication. However, this is not true of all autistic people and may not have been relevant to any of the study participants.

From my time as a support worker, I understood that any participant would have a personal folder that outlined ways of communicating and engaging with them, along with numerous risk assessments detailing any known issues that could occur and the best ways to act in these situations. Therefore, the stipulation that a researcher must receive a favourable ethical opinion prior to the recruitment of participants reduces their ability to create methods that are appropriate for the eventual study. Researchers without experience of autism, learning disability or support services may find it hard to imagine the diverse situations that could arise when developing studies in these contexts, yet working

with a support service to design a study would likely result in methods appropriate for the research context whilst also reducing the risk of harm to those involved. Perhaps it is suggestive of an ethics process that has yet to respond to the development of social science research – particularly inclusive and ethnographic methodologies in which engagement in unforeseen events is an innate part of much fieldwork (Atkinson, 2014, p. 5) - and that favours methods of research with fixed procedures and environments. The corollary of this is that, as Boxall and Ralph (2011, p. 175) argue, researchers are dissuaded from developing inclusive research involving people with learning disabilities as they fear an ethics committee may not deem it justifiable (an example of such a decision was experienced by Andrews (2017) during his PhD study).

An important consideration arose relating to the participatory nature of the research and the roles of potential co-researchers and research collectives: should I provide them an opportunity to be published as co-authors in future articles that feature the data they collect? This question was asked in my probation mini-viva and then again by the SCREC. It was decided that, although the co-researcher's position and the data they would collect were important to the design of the study, offering them co-author opportunities could result in future complications when attempting to contact them in regard to potential publications. The primary risk was that parts of the study could be compromised, as I might not be able to secure permission to publish the relevant data. If this was the case, the research would have wasted the time of those involved to the detriment of its ethical integrity. The issue of co-production is currently prompting discussion from a number of researchers (Bertilsson Rosqvist et al., 2019; Brownlee-Chapman et al., 2018; Cook, 2012; Hall, 2014; Holt, Jeffries, Hall, & Power, 2019; Rix et al., 2020; Seale et al., 2015), with concern as to what kinds of participation constitute an inclusive approach and how different research practices effect representation of voice. What appears common across inclusive studies is their 'messy' nature (Holt et al., 2019, p. 3): a regularly reported theme that shows the complex task researchers undertake when attempting to represent the voices of diverse people and develop opportunities for meaningful research participation. I would argue that my study is inclusive in nature as it aims to represent the voices and experiences of persons who would rarely be included in research and to do this asked their social and support circles for input; the opportunity of co-authorship could be another method to enhance its inclusive nature however its associated risks outweighed the potential benefits.

Fieldwork Methods

This section describes the study methods and how they aided exploration of Ben's experience of everyday life at the day service. It details the practical process of thinking phenomenologically while doing phenomenology, to demonstrate how it shaped fieldwork and ultimately led to a new method with which to examine the phenomenon. The study began as Berndtsson et al. (2007, pp. 262-263) recommend – with an initial phase in which to observe and learn about the participants within their everyday context – though with the addition of a support worker co-researcher to aid the process. Following this initial phase – and in an attempt to maintain an ongoing consideration of lifeworld ontology within the study context – fieldwork was structured to incorporate intermittent analysis stages that aimed to uncover significant aspects of experience that could shape subsequent periods of data collection. After each fieldwork stage, the collected data was analysed using lifeworld fractions (Ashworth, 2006, 2016) and the results suggested some of the unique ways that the phenomenon is experienced by participants.

I began the fieldwork with no clear expectation of how long it would last, as a lifeworld approach asks one to explore the phenomenon as experienced as fully and openly as possible (Ashworth, 2006, p. 219); in other words, there was no clear guidance on the amount of evidence needed to explicate the meaning of everyday life according to Ben and so this would be assessed at each intermittent analytic stage. Hodge (2008, p. 31) notes that lifeworld researchers using interview methods should 'listen, feedback, check with the participants that the experience was 'captured' accurately, amend (if required), feedback, etc.'. Here, where interviews were not possible for data collection, this meant looking for recurring situations and asking whether further fieldwork would reveal additional aspects of experience with significance to Ben, whether particular moments required closer inspection and whether the central phenomenon of everyday life at the day service had been thoroughly investigated.

I planned each stage to last three weeks to allow the day support service adequate notice. Subsequent to fieldwork stages, I planned a two to three week analysis stage, informing the day support service when I planned to return. The eventual structure of the research involved three stages of fieldwork and analysis and so this section will follow its chronology accordingly, providing justification for the methods involved at each stage – as well as those not chosen – and discussing how they related to lifeworld ontology in the study context.

5.8 Stage 1 – Fieldwork methods

Participatory Observation

The initial stage involved nine days (8.50 a.m. – 3 p.m.) of fieldwork over three weeks. The primary method of data collection was participatory observation which involves a researcher collecting data while socially interacting with participants in their everyday lives (Heinonen, 2013). The purpose of this is to learn about the milieu in which participants live and experience and to develop an understanding of their social and cultural practices (Oeye, Bjelland, & Skorpen, 2007, p. 2299). In practice, participatory observation meant spending time with Ben as he attended the day support service, joining him as he arrived in the morning and accompanying him to the different places to which he went. It was vital that data could be collected in this way, as exploring Ben's experiences required one to make sense of his communication through its relationship with its social, spatial and temporal contexts (Bradley, Caldwell, & Korossy, 2015; Simmons & Watson, 2014b, pp. 151-153). By coming to know and understand the expressions Ben made in response to different situations, and by sharing in the situations myself, I could begin to gain evidence of the some of the unique ways that he was experiencing everyday life at the day service.

An alternative non-participatory observation approach – where the researcher attempts to minimise the impact of their presence on observed events by maintaining a distance between themselves and participants – could be argued as a more effective way to gain access to the natural attitude of a study context and research experience as it is lived day-to-day. However, the difficulties of a researcher blending into the background of a busy day service cannot be understated and this was demonstrated through the regular interest that inhabitants and support workers took in my attendance. Gaining access to a day service immediately marks one out as something different to usual proceedings, as staff and inhabitants are informed that an outsider will be conducting research – information leaflets on the walls only highlighting this. Some support workers were nervous of my presence and in one case this led to a person not consenting to be observed supporting Ben (ethno notes, 9th April). Through participatory observation in which I engaged with support workers and inhabitants, conversing with them as they do with each other, and joining in with activities where possible (e.g. using gym machines alongside Ben and his support worker), I was gradually accepted as part of normal life by the day service community. This view was demonstrated by small but significant changes in support workers' actions, such as asking Ben to wait as they took a cigarette break when they had not in previous weeks, or requesting that I made them cups of tea. As I began to share in these everyday regularities, I could begin to orient myself towards the taken for granted ways in which life happens at the day service.

The specific method of data collection was a fieldnotes approach previously developed by Simmons and Watson (2014, pp. 155-156) when exploring the experiences of a child with profound learning disabilities within school environments. This involves taking highly detailed notes of small events involving the participants that focus on: how and what they communicate, the moments that lead up to and after the communication, the environmental and temporal contexts, and how others engage with the person: an example is provided below. I attempted to record as much as detail as possible, filling in a small note pad as I went with Ben to such places as the cinema, gym, restaurant and bowling alley. The method enabled me to be versatile: I could take notes wherever Ben chose to go and in this sense I was a participant in his day-to-day life. Ashworth (2006, p. 219) argues that phenomenological researchers should set ‘...aside their own criteria of truth and reality... to turn their attention to the actual talk and activity of the person so as to discover the meanings of that person’s – possibly quite unique and idiosyncratic lifeworld’. I met Ben at his level - respected and valued his language to allow him to naturally convey experiences using his personal methods of communication. This was a commitment to Ben’s voice.

Ben arrives at about half 9. He sits at the same table as the past two days, next to the other person who had just arrived with his mum. This person is now doing a jigsaw. I give Ben the thumbs up and he nods at me and looks away. His support worker, Emma, brings him two choices of films that are printed on A4 sheets of paper. She asks what he would like to see today and Ben taps the paper with Dumbo on. She then gathers two squash bottles from the kitchen and presents them to Ben who chooses apple. He puts his fingers in his ears for 10 seconds then crosses his arms and begins to observe the man doing the jigsaw. He watches intently, occasionally putting his fingers in his ears but keeping his eyes on the jigsaw. He smiles for a few seconds and appears calm and contemplative (lifeworld notes, 3rd April).

Others who have conducted qualitative research with people with profound learning disabilities, such as McCormack (2017, p. 80) and Kaley, Hatton, and Milligan (2018), have video recorded participants to gain a closer understanding of their communication repertoires and enable closer analysis of particular events. Aside from presenting ethical difficulties relating to video recording within a day support service, I felt that at this initial stage that this particular method had further drawbacks that could bring the study’s inclusive approach into question. Primarily, I was concerned with *damastism* (Lahlou, 2011, p. 608) – a reference to the Greek bandit Damastes who contorted and maimed his victims to fit an iron bed - where data collection or analysis is guided by a researcher’s own expectations of the study results. While observing Ben, it would be my responsibility to record the events that I interpret as demonstrating his experiences of the study phenomena. The issue here is that I would be unable to simultaneously

reflexively analyse why I was choosing these particular moments due to the attention required of video recording in a busy day service and that I would also create a reliance on the recordings to yield results when analysed. In contrast, the benefit of the Simmons and Watson method is that one can make reflexive notes as one makes observational notes, and that it is possible to document many events across a day which means less dependence on single moments to reveal significant aspects of experience. As such, the method was appropriate for the initial stage in that it enabled a broad and open exploration of Ben's lifeworld within the study context.

A further issue in video recording at a day service was the degree to which it could affect the behaviours of support workers (Lahlou, 2011, p. 609). Drawing from my own experience as a support worker, I felt that video recording would lead to situations in which support workers altered how they engaged with Ben and other inhabitants to demonstrate what they thought to be 'best practice' – the ways that the service advises support workers to engage with inhabitants – as opposed to everyday examples of support. The study's objective to explore how young autistic adults experience everyday life at day support services may, therefore, have become compromised as Ben experienced a different version of the phenomenon. Although this risk remained when using a note taking method – there was evidence of it during fieldwork as a senior member of staff appeared to pay extra attention to Ben and his support workers than those of their peers (ethno notes, 1st April), and when a support worker mentioned that they felt weird when I first began observations at the day service (ethno notes, 3rd April) - I would argue that it was minimised as it is far less explicit or intrusive than a researcher directing a camera. The note taking method also gave me opportunity to engage with Ben and his support workers which, as relationships formed and trust grew, was noted by support workers as easing tension surrounding observations (ethno notes, 17th April).

The corollary of this is that as I began to become an everyday part of the service, not unexpected or out of place, I could myself experience some aspects of the study phenomenon in a natural way – those that relate to lifeworld fractions (Ashworth, 2016) such as mood-as-atmosphere or spatiality. In this way I could adhere to the advice given by Berndtsson et al. (2007) and begin to share in Ben's lifeworld and assume the natural attitude as it related to his experiences at the day service. In practice, this meant that I became more astute at noticing and recording the particulars of Ben's day such as small recurring moments or the ways in which he engaged with different support workers.

5.9 Support worker co-researcher participatory observation

A further attempt to reduce the risk of damastism was to ask a support worker to also collect data relating to Ben's experiences. That is, by asking others to contribute their perspectives, there would be less reliance on the events that I observed to generate compelling results and that to some extent, my voice would be balanced by those of the people who share everyday life with Ben. Asking a support worker to become a co-researcher acknowledged that they, by virtue of their career roles and everyday experiences of engaging with autistic people within a day support service, could be considered insider experts of the study context. This is a foundational element of inclusive research that regards the positioning of participants as 'instigators of ideas' (Walmsley & Johnson, 2003, p. 10) as vital to producing research that is responsive to the lived experience of the related social group. Specifically, I was aiming to utilise the communicative repertoires that are shared between support workers and those they support – those that develops over months and years and across a multitude of diverse scenarios – to provide further insight into the day-to-day experiences of Ben.

In theory, inclusive research design should provide participatory co-researchers with data collection methods that are appropriate to their specific communicative and social contexts (Seymour, 2001, p. 159). Online spaces – where co-researchers can discuss and contribute ideas or information through online forums – are a recent example (Liddiard et al., 2019) that have provided researchers with life-limiting and life-impairing conditions the option to work from a computer and outside the typical Monday-to-Friday, nine-to-five, meaning that they could participate according to what was appropriate to their schedule, such as periods during the night or when support assistants were present. In practice, however, this kind of development and planning requires a prior engagement with potential participants that is rarely afforded within the financial and temporal parameters of academic research (see Olsen & Carter, 2016). These restrictions are heightened in the context of a PhD study which led me to rely on my experience of support work to consider which methods could be used by support staff. I began with the stipulation that the method would not require staff co-researchers to participate outside their usual work hours, as I thought this could be ethically questionable in relation to a job role that requires high levels of commitment with little financial reward (see for instance Vassos, Nankervis, Skerry, & Lante, 2013). Further to this and following similar studies (Gaudion, 2015; Hill et al., 2016; Simmons & Watson, 2014b) was my contention that the participants' experiences would be best understood if data was collected in situ and that this required a participatory observation approach.

I was aware that support workers are often asked to complete paper work as they support a person, such as behaviour monitoring charts or food intake records, which suggested that it would not be impractical for the co-researchers to use the same Simmons and Watson (2014b, pp. 155-156) note taking method as myself. An alternative option would have been to ask them to take photographs that depict the experiences of the participants and provide a subsequent description in writing; however, in contrast to the note taking method, this would have required them to set aside periods of their shifts to consider and write about their photos which I anticipated could cause undue work pressures. Outside of the practical implications of these methods, I thought that note taking could achieve a sense of balance between myself and the co-researcher as they would be interpreting Ben's experiences through the same lens as myself. Furthermore, as support workers demonstrate a degree of observational writing skill as they are required to document their work on a daily basis, and that the note taking was not overly complex with many supporting examples in the Simmons and Watson book, it was feasible for me to teach the method to the co-researcher during a short meeting prior to the fieldwork beginning.

It was agreed that the co-researcher would aim to complete observations once a week while supporting Ben, though they would stop at any point if they felt that it was compromising their ability to support him. Over the course of the first stage, they made fieldnotes on four separate occasions, each spanning a morning (approximately 9 a.m. – 12.30 p.m.) or an afternoon (approximately 1.30 p.m. – 3 p.m.). After two weeks they sought assurance that their method was appropriate and after reading a couple of passages, I confirmed that it was.

5.10 *Ethnographic 'hanging out'*

The central phenomenon of this study - *everyday life at day support services* – began with minimal focus due to the lack of previous empirical work that I could draw from and this meant that the study required an appropriate method to reveal some of its phenomenological features. To put it another way, there may be some general ontology related to everyday life at day support services – for example, in a way that relates to the notion of directed awareness (Merleau-Ponty, 1962), inhabitants may be guided by what support workers direct themselves toward (to borrow from the previously mentioned Claesson (2002) prison classroom study) and thus this concept could provide ways of exploring the phenomenon more acutely. However, such claims could not be established so it was important to characterise everyday life from a phenomenological perspective as part of understanding the interrelated nature of Ben's lifeworld and the study context.

Ben arrives at the day service around 9.30 a.m. Although he leaves to pursue hobbies and interests, approximately 60% of his day-to-day life is within the day service building, depending on factors such as the changing times at which he leaves for the cinema. Most service staff – support workers and managers – arrive just before 9 a.m. and from here inhabitants gradually flow in, coming and going depending on their own schedules. For Ben and many others then, the day service is a shared space in which they experience each other in a social world. They affect and are affected by each other and so share in some taken for granted ways of being in the world, termed the natural attitude (Berndtsson et al., 2007, p. 259). If, for example, an unknown researcher turns up unexpectedly one morning, it is likely that it is not just felt by one person but across the lifeworlds of those connected to everyday life at the service as it confronts their pre-conscious understanding of what life is like; of course, strangers may regularly turn up and this may be ‘business as usual’. To explore the natural attitude required me to participate in everyday life at the day service, to learn about its constituent parts by observing and engaging with the people that experience themselves as part of it. The participatory observation approach with which I would research Ben’s experiences was therefore also appropriate for this task.

Participatory observation here refers to an ethnographic phenomenological method in which the researcher ‘hangs out’ in the study context to learn about the experiences and practices of its related people. Hanging out is an often cited part of ethnographic approaches aimed at gaining an insider perspective on a social group (Kusenbach, 2003, p. 463). It involves a researcher immersing themselves into the everyday situations of their participants in order to learn of their experiences, relationships and customs. Researchers working with people with profound learning disabilities have found particular value in this method (see Goode, 1994; McCormack, 2017; Miettola et al., 2017) as they argue it enables an emic (insider, empathetic) as opposed to etic (outsider, clinical) perspective (Goode, 1992). This occurs over time as the researcher orientates themselves toward the idiosyncratic ways that people with profound learning disabilities and their significant others relate to and live with each other; in doing so, they are able to discard some of their preconceptions and attend to the meaning of the situation for the participants. To some extent then, hanging out is a pathway to gaining a sense of the natural attitude of a research context and was therefore chosen as way to begin thinking phenomenologically while doing phenomenology.

Criticism of hanging out as an ethnographic phenomenological approach focuses on its failure to systematically examine a phenomenon from the perspectives of those that experience it and in doing so may lead a researcher to lose sight of significant aspects of experience in the abundance of data (Kusenbach, 2003). An alternative that is ‘at the same time more limited and more focused’ (Kusenbach,

2003, p. 463) is 'go-along' ethnography in which a researcher targets particular areas of a phenomenon as defined by spatial and temporal contexts – for example, the lunch period at the day service – and explores how a group of people experience it by informally interviewing them in situ, either across multiple one-to-one instances or in groups. The benefit here is that the researcher collects a coherent set of data that can illuminate shared ways of experiencing the phenomenon which is in turn another way to discover the natural attitude of a research context. Although this could be effective in exploring everyday life in a day support service, I would argue that there are two particular problems in relation to this research: first, it would be presumptuous to pick a certain spatial/temporal context at the initial stage of the study as there was a lack of understanding around significant areas of everyday life at day support services. Second, in asking the researcher to conduct multiple interviews, the method prioritises verbal communicators and would necessarily exclude many of the inhabitants from contributing their perspectives: a fraught epistemological approach that would challenge the inclusive aims of the study. In contrast, hanging out enabled a way to value the communicative approaches of any person that entered the day service, providing a method that could draw me closer to the natural attitude as it appeared to both inhabitants and service staff through their shared day-to-day context. Furthermore, the concern that significant aspects of experience might have been overlooked was attended to as I highlighted, considered and checked emerging ideas through the continually reflexive and reflective process of thinking phenomenologically while doing phenomenology.

In practice, hanging out meant that I made ethnographic notes that focused on the minutiae of everyday life at the service. This included detail on who was part of it - what they did, how and where they did it, how they acted with and around each other, what and how they communicated - as well as information on spatial and temporal contexts and reflexive notes relating to my own thoughts on observations and how the research process may have been affecting the situation – an example is given below.

It is lunch time back at the day service. Ben has arrived back. There are three support workers attempting to persuade a man to eat his lunch. The manager comes out and says to him 'you must eat your lunch come and sit down'. He follows and begins sitting down at the same table as Ben, though stands up and walks off with a sandwich. As he walks about, 2 support workers discuss why he isn't eating, mention that he seems slightly unsettled. One says 'it's the moon' (ethno notes, 15th April).

A notepad was used to record both observations of everyday life and of Ben's personal circumstances, marked with a '*' to signify the former, and a '-' to signify the latter. This took place on the three days

that I observed Ben each week, arriving at 8.50 AM in the morning to begin observations – ten minutes before the majority of support workers were due to start – and continuing until 3 p.m.

As I accompanied Ben through his day-to-day schedule, I moved accordingly to different areas of the day service building as well as occasionally leaving and returning. Although it could be argued that this meant that I was missing much of the activity of the day service as the focus remained distinctly on life around Ben, it was clear that the shared experience of everyday life at the service happened in one particular area, named the Hall, and as Ben spent much of his time there, the natural attitude of this spatial/temporal context could be investigated in tandem. It is important to acknowledge that some inhabitants arrive and immediately depart for the day, spending almost no time at the day service building, while others do not ever go in and pursue their interests away from the service building. If this had been true for Ben, the hanging out method would have been inappropriate to research the phenomenon of everyday life at day support services as events in the service building would have had little bearing in his lifeworld. This is part of the initial step of thinking phenomenologically while doing phenomenology: to adapt the method to the phenomenon, participant and study context.

I have outlined three methods of participatory observation that I used to conduct the first stage of fieldwork and provided justification for their inclusion. Throughout this period, I transcribed notes verbatim into a digital format and this resulted in two data sets: that which related to Ben's lifeworld and his experiences of everyday life at the day service, and that which related to the phenomenon of everyday life at the day service. Of course, certain notes related to both data sets and were assigned accordingly.

5.11 Stage 1 – Data Analysis

Nvivo 11

Nvivo 11 is a qualitative data analysis software that I employed throughout analysis. To do this, I took the transcribed data sets that existed as Word documents - each day of data collection representing two documents (lifeworld notes and ethnographic notes) - and uploaded them to Nvivo. Within Nvivo, these are referred to as sources and are shown in the image below (Figure 1) – i.e. 'lifeworld 10th April' is a source that contains all the fieldnotes I made in relation to Ben's lifeworld on 10th April. From here, Nvivo allowed me to view the sources, on which I could assign notes or thoughts before then starting the coding process. Below I will describe and illustrate this method.

1st stage		
Name	Nodes	References
Lifeworld 10th april	262	654
lifeworld 3rd april	231	613
Lifeworld 8th april	263	681
lifeworld 9th april	188	430
Lifeworld notes 16th april	253	598
Lifeworld notes 17th april	228	410
Lifeworld obvs 2nd apr	223	626
Lifeworlds Ben 1st ap	198	524
LW 15 april	267	758

Figure 1: Example of Nvivo lifeworld analysis

5.12 Lifeworld Fractions

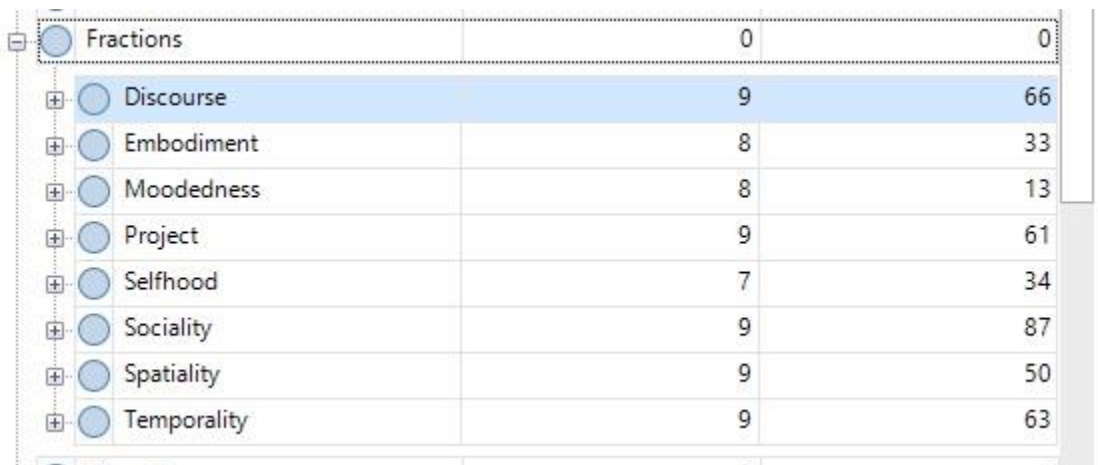
Analysis of both data sets followed a similar process. I began with data that related to Ben's lifeworld. This was read through multiple times to provide me with a sense of it as a whole as well as its constituent parts – a way of lingering in the situations that I had been in and recorded in an attempt to open my mind to the possibilities of what they may mean for Ben (Finlay & Molano-Fisher, 2008, p. 258). Subsequently, I followed the two stage, lifeworld fractions analytic method as described by Andrews et al. (2019). During this, I adopted the epochē which refers to a process of bracketing assumptions about the phenomenon in order to remain with the experience at hand (Ashworth, 2016, p. 21). I had to view the world from Ben's position as it appeared in the data. Although this includes discarding theoretical concepts, the fractions necessarily appear when considering any experience as they are the constituent parts of its existence. It is therefore appropriate to orientate oneself towards a participant's lifeworld experience by examining data through the scope of the fractions.

First stage: The purpose here is to find how the data relates to lifeworld fractions. This is done by coding words, phrases or sections in relation to the relevant lifeworld fractions:

We arrive at the cinema and it is the school holidays so the foyer is quite busy with families (*spatiality and temporality*). Emma and Ben walk up to the counter and Ben takes off his bag and takes out his wallet and gives it to Emma (*spatiality, selfhood and sociality*). He stands to the right of

her, slightly behind and she books the tickets (*sociality and spatiality*). He watches over her shoulder, directing his gaze at her hands and the man behind the counter (*sociality and project*). The tickets are printed and she shows Ben, clearly stating that we are in screen 4. He nods (*sociality and discourse*). (lifeworld notes, 3rd April).

This was completed across the data set until each of the eight fractions were assigned all relevant data. This is illustrated below - the numbers on the left indicate the amount of sources from which data was assigned, while the numbers on the right indicate the amount of individual parts of data (words, phrases or sections) that were assigned to the fraction. In relation to sociality for example, 87 parts of data were found in 9 sources.



Fractions	0	0
Discourse	9	66
Embodiment	8	33
Moodedness	8	13
Project	9	61
Selfhood	7	34
Sociality	9	87
Spatiality	9	50
Temporality	9	63

Figure 2: Lifeworld fractions within Nvivo

Stage two: The aim here was to orientate myself towards the phenomenon (everyday life at the day support service) through Ben's experience of it. This was done by examining each fraction in turn and asking of the data: in relation to this fraction, how is Ben experiencing the situation? In answering this question, I generated codes - termed 'units of meaning'. I will demonstrate this using the following extract:

She disappears and reappears again holding another two sheets with pictures of 2 cinemas. He again taps one quickly, then continues watching the person complete the jigsaw. This person is vocalising quite loudly, 'eeeees', 'ahhhhhhs' and 'chup chup'. Emma brings out 2 bottles of squash saying nothing, Ben touches the summer fruits and Emma goes into the kitchen to get him this. (lifeworld notes, 10th April).

In relation to selfhood and the situation, the passage suggests that:

- Ben experiences himself as provided for in that drinks are brought out from the kitchen to him.
- Ben experiences a sense of autonomy in the opportunity to choose a drink and film.

In relation to sociality:

- Ben is drawn to the activity of others as he observes them.
- Ben sees support workers as providers (of choice or refreshments).

In relation to discourse:

- Ben speaks of his plans and choices through physical direction. He embodies his talk.

In relation to temporality:

- Ben sees the future of his day communicated to him through a picture of the cinema.

In relation to project:

- Ben is able to pursue his interests in cinema, confirming it through the action of pointing.

It is important to note that units of meaning frequently relate to multiple fractions – so in the above example, those units of meaning described under selfhood also relate closely to sociality and similarly, the experience of discourse also relates closely to embodiment as Ben uses embodied communication to speak of the situation. This is inevitable as Ashworth (2016, p. 23) does not mean the fractions as distinct entities but as interrelated horizons in which meaning flows between one another. As the above example demonstrates, one small situation relates to experience in multiple ways and it is this process of analysing from each fractal perspective that can highlight meaning as felt across the lifeworld.

When asking how Ben was experiencing a situation, I considered both the data at hand as well as what I had come to understand from other areas of data and my time doing fieldwork. To take the above example, I knew that the offer of the drink from his support worker was not unique to this situation as I had observed it happening every morning that I observed Ben arrive at the day service. Furthermore, each week on this morning he chose the film in the same way before subsequently going to the cinema and he also regularly observed the same person completing jigsaws. One may also note that this always occurred in the same area of the day service. This is part of the process of gaining an insight into Ben's taken-for-granted experience. I considered over and over the ways in which situations appeared to him – how he acted and responded, how this was similar or dissimilar to other situations, where and when it happened, how others acted toward him, the ways in which he expressed himself and what this meant for the situation. As the analysis progressed, units of meaning became more or less concrete though never

certain. They were always available for questioning, particularly when understandings arose in other areas. For example, when examining the Project fraction it became evident that Ben was drawn to pursuing hobbies and interests in particular spaces – such as a particular treadmill at the gym – but it was only during analysis of the Spatiality fraction that this could be further expanded on, suggesting ways in which Ben saw areas as his own personal space and a connection to a temporal order of a day. The image below shows the Spatiality fraction and the units of meaning that I had identified at the end of this initial stage.

Fractions	0	0
Discourse	9	66
Embodiment	8	33
Moodedness	8	13
Project	9	61
Selfhood	7	34
Sociality	9	87
Spatiality	9	50
Adapting	3	5
creating personal areas	7	17
locating time in space	7	30
project in familiar space	8	28
Space and place	3	6
stillness throughout	7	10
Temporality	9	63

Figure 3: Units of meaning within Spatiality fraction

The result of this process was that some units of meaning and their related fractions appeared more significant than others, either by having larger amounts of data attached to them (as in the case of ‘project in a familiar space’ seen above), or, in the case of some units of meaning, by being related to multiple fractions. These units of meaning and fractions were suggestive of the particular ways in which Ben was experiencing everyday life at the day service. It was with these signposts that I explored lifeworld ontology, considering how this may reflect the world as it is perceived by Ben through the way in which the analysis was suggesting it to be, while also paying attention to how this may aid new ways of researching the study phenomenon. It is important to acknowledge that this was the first stage of a reflexive and reflective process in which I remained open to the possibilities of the phenomenon and Ben’s lifeworld; it ‘should not be seen as a theoretical screen, but something that made it possible to see the complexity in the field of study during the field phase’ (Berndtsson et al., 2007, p. 267). Throughout, I kept an analysis diary in which to record thoughts and on-going developments, and to give me a way to

question the relationships between evidence (data), phenomenological theory and my own perspective. This was also discussed during supervision meetings. I will now detail this exploration of lifeworld ontology.

5.13 Lifeworld Ontology

Sociality, selfhood and project.

The analysis brought to light an intensely social aspect of Ben's everyday life that appeared to also be felt in other areas of his lifeworld – appearing namely in selfhood and project fractions. The units of meaning that appeared significant, either due to their prominence across fractions or through holding significant amounts of data within individual fractions, were:

- Autonomy: Ben's experience of autonomy appeared on the one hand as taken by him and lived through in many areas such as pursuing hobbies independently, while on the other hand it also appeared to be dictated by and provided to by support workers as they menial tasks for him such as getting a drink in the morning.
- Expectation of others: Ben appeared to know precisely what support workers would do before they did it, monitoring their actions closely in expectation.
- Observation of and interest in others: Ben appeared drawn to the activity and actions of others, spending periods of time observing inhabitants, support workers, myself and members of the public.
- The supported: Ben's support workers led some situations despite Ben appearing to have a better understanding of the task, such as what card to provide to reception at the gym.
- The independent: At times, Ben left the company of his support workers and went about his pursuits completely independently.
- The supporter: Ben guided support workers in certain situations – directing them with actions and vocalisations in an exchange of roles.

As these units of meaning were closely related to sociality – how Ben experienced himself and those around him and the affect they had on each other – I consulted the phenomenological works that Ashworth (2006, p. 215) points to when defining sociality as a fraction, those of Aron Gurwitsch (Gurwitsch, 1962, 1979) and Alfred Schutz (Schutz, 1976). Both have sought to define everyday

experiences in a social world, exploring how situations are typified in relation to the 'modes of procedure and conduct regarded as correct, good, and natural by the society in question' (Gurwitsch, 1962, p. 66). These are preconscious ways of being with others and exist in relation to one's biographical situation (your entire history) and how we expect others to conduct themselves in the situation. One typifies another and expects them to act in a certain way, which at the very same time relates to how you will act before them – you typify yourself (see yourself as something in the situation). (Here one sees how the fractions of selfhood and sociality flow into one another.) In these situations, both partners are attempting to pursue some project and so one relies on the typification of the other, as well as how one understands them to typify oneself and what one senses their project to be – 'a reciprocity of this sort prevails in all social interactions' (Gurwitsch, 1962, p. 68).

Within particular social contexts, typification becomes a shared process as people intuitively respond to others in the 'typical' way that they understand as appropriate for the situation. This is what Schutz (1976) refers to as common sense knowledge – the taken for granted ways in which people share an understanding of how to act around each other – a 'reciprocity of perspectives' (Gurwitsch, 1962, p. 62). This appeared to have relevance to the units of meaning that I found during analysis in that Ben and his support workers seemed to have particular ways of interacting with each other that were based on what they understood the situation to be – that shared between a 'service user' and a support worker. For instance, support workers (in general) would often do the same menial tasks for Ben (e.g. taking money out of Ben's wallet and paying at gym reception) and he appeared to expect this to happen – they just understood what to do even if the support worker had not previously worked with Ben. The Simmons and Watson (2014b, pp. 155-156) note taking method appeared to be capturing these interactions to a large extent and I did not feel that there was a more appropriate method that I could effectively utilise in the various situations of Ben's day-to-day life. I did however go into the second stage of fieldwork with a focus on interactions between Ben and his support workers, looking for small differences or similarities in the way he interacted with different people, while considering how and to what extent he and support workers knew each other (their histories together, how regularly they interacted and how support workers talked about Ben). One may argue that formal interviews of support workers may have aided this understanding though I felt that it was important to remain with Ben and the situations he finds himself in as it was in this minutiae that reciprocity could reveal itself. Furthermore, I had found that support workers were voluntarily providing their perspectives, talking to me about how and why they interacted with Ben in certain ways.

5.14 *Temporality and spatiality*

Two more fractions that appeared significant at this stage were Temporality and Spatiality. The related units of meaning were:

- Expectation of order – Ben had a very specific way in which he thought the day should transpire, expecting others to respond to this accordingly.
- Creating personal areas – The areas that Ben used through each day were very specific and, in examples like the specific treadmill at the gym, appeared to be related to as his own, personal space.
- Others supporting or challenging the structure – At times, the people that Ben encountered, generally support workers though others also – presented as barriers to the structure of the day that he expected, and this would provoke fright or upset.
- Reliving the past – Ben days were structured in the same way each week, seemingly experiencing the same Monday, Tuesday and Wednesday over and over.
- Disappearance of time – When Ben's expectation were fulfilled, he seemed to momentarily lose sight of the next step in his expected schedule and experience a relaxed state.
- Locating time in space – The spaces Ben visited seemed to signify the order and temporal running of his day.

Ashworth (2016, p. 28) points to the work of David Seamon for an in depth exploration into the phenomenology of space. People are emotionally linked 'with environments, places, and landscapes' states Seamon (1984, p. 757), 'ranging from momentary emotional irritation one feels when a thing is out of place to the profound sense of attachment and concern people may feel for a place they consider sacred.' To explain this from a phenomenological perspective, Seamon (1979, p. 46) draws from the notion of body-subject as described by Merleau-Ponty (1945), referring to the ways in which our bodies intuitively know how to move – we do not need to tell our feet to move in order to walk, it just happens – and in this way, our bodies are intelligent, attending to the everyday situations of life without any conscious direction. This notion is echoed in what Seamon (1979, p. 75) describes as feeling-subject, which is the innate ways in which we feel in situations – for example the fear that one may feel when walking through a dark alley, which, when coupled with the physical unease in the belly that arises from body-subject, may make for an overwhelming experience.

What is important is that both body-subject and feeling-subject learn how to respond to everyday situations through the environments we find ourselves in and this eases the extent to which we need to pay conscious attention to our pursuits (Seamon, 1979, p. 77). The more we take part in something, the more accustomed our body-subject and feeling-subject become. On a small scale this is termed a 'body ballet' (Seamon, 1979, p. 55), so learning to tie one's shoe laces can be frustrating to begin with as the body learns the required movement, however this requires little or no conscious attention once mastered. Extending from this are 'time-space routines', which incorporate a number of learned bodily behaviours over a longer period of time that are connected to particular environments: if we go to the shop and buy groceries, in most circumstances there is little thought put into the experience as we walk there, carry a basket around, pay, say thank you and walk home. If however, we were in a different city, this may require far greater efforts as our body-subjects are not accustomed to the situation, perhaps also triggering the feeling-subject.

The analysis had shown Ben to have a very specific way of moving through his days, linked with particular activities happening in particular places in a particular order. When this was challenged, I had observed and noted that it could cause Ben distinct upset, communicated through facial expressions, verbalisations and physical actions. In some ways, this related to the description of time-space routines in that it appeared that Ben's feeling-subject would be triggered when his body-subject was confronted with an unexpected situation, and this seemed to have a defining effect on Ben's everyday experiences. For this reason, I decided to look closer at the ways in which routines were a part of Ben's daily life in the second fieldwork stage. Through the previously described Simmons and Watson (2014b, pp. 155-156), I would adopt a perspective that included a focus on the patterns in Ben's day-to-day journey, looking particularly at the ways in which he moved through and within environments, and how this was effected by different events such as the actions of others or the surrounding environmental context.

Another way of considering temporality from a phenomenological perspective is through the concepts of protention and retention (Heidegger, 1962; Kwan, 2017) – the former being concerned with the temporal future (its potentials, hopes and fears) while the latter looks to the temporal past (its settled memories). These form a temporal horizon that are part of the experience of any life situation, so for instance as I go to pay for a coffee at a café, I experience a future in which the person takes my money and provides me change, while I also experience my past in which similar events took place, and these form my context of understanding during the event (Kwan, 2017, p. 1729). How I experience pasts and futures changes my context of understanding, so if I had previously been short changed at this café, this experience of the past may mean I experience a number of potential futures in which the same happens, or where

they surprise me with excellent service and so on and so forth, and thus my experience may intend towards the actions of the till person. One generally does not consult these futures or pasts in everyday situations though they are always present in our experiences. As the 'reliving the past' and 'expectation of order' units of meaning highlighted, temporality had significance in Ben's daily life and this could perhaps be understood as a constricted temporal horizon meaning that Ben's context of understanding was often concerned with an imminent future (what he was doing next or that day) as opposed to further into the future. To explore this further in the second stage of fieldwork, I would look for further evidence of Ben's protentive and retentive horizons during observations, such as instances of planning or precaution (Kwan, 2017, p. 1740) and the contexts in which these occurred.

5.15 Summary: Stage two lifeworld fieldwork direction

To explore Ben's lifeworld in the second stage of fieldwork in accordance to the analysis of the first stage and its associated phenomenological theory, I continued with the same Simmons and Watson (2014b, pp. 155-156) note taking method though with a more defined focus on:

- The ways in which Ben and his support workers interacted including differences or similarities between support workers and how they looked to anticipate one another, with added reference to how they knew each other (e.g. how often they worked with each other, the ways they spoke of Ben or the particularities of their relationship).
- Routines within Ben's days and how these related to movement, environment and their surrounding contexts – from small patterns such as a repeated interaction between him and a support worker to larger patterns such as the activity and movement involved across a morning.
- The ways in which Ben looked to the future through planning, direction or action, the temporal dimensions of this future (e.g. something happening later that day or in the next few moments), how this may have links to his past and how it was affecting situations.

To keep these ideas at hand through data collection, I briefly outlined them at the front of the notepad in which I recorded observations and subsequently read through them each time I arrived at the day service. It was important not to view these ideas as a list with which to define observations and the events that I needed to record as I had to remain open to the possibilities of Ben's lifeworld. They were however a scope with which I could ask questions of situations as they were occurring, recording my observation of

the event and my thoughts in relation to the results of the aforementioned analysis. In the following example I considered notions of routine and temporal horizons:

He cycles for a moment and then takes his shoes off and readjusts his socks, then puts them back on and resumes the 5 minute cooldown. I note to myself that he does this more or less at the same time every week though one would expect an uncomfortable sock could appear at any time. It is as though this discomfort is felt at the time and place of which he knows it to be felt – this may suggest something of why transitions from place to place/activity to activity can be so difficult as he may not be able to help but feel a sense of anxiety in relation to it (lifeworld notes, 10th June).

Note that this small moment in which Ben readjusted his sock may have had little or no meaning if observed once or twice – it may not have even been noticed – yet the repeated situations that I shared with Ben, as well as how the initial stage had attuned my perspective, enabled a possible view of Ben's experience.

5.16 Analysis of the phenomenon of everyday life at day support services

Analysis of the second data set happened in a similar manner to that of the first, reading and lingering with the data before beginning the two stage analytic process (Andrews et al., 2019): coding words, phrases or sections to the relevant lifeworld fractions before looking more closely at each fraction for units of meaning. In this case, the question I would ask of the data was: in relation to this fraction, what does this situation suggest about everyday life at the day service? Once this was complete, the fraction of Sociality and its units of meanings appeared particularly significant as they also linked closely with units of meaning found in Project, Spatiality and Temporality. The units of meaning were:

- Hobbies and activities – The day service was a place of activity, often busy with people (inhabitants and support workers) taking part in activities either by themselves, in pairs or in groups. This fluctuated as some pursued activities outside of the day service while at other times people arrived to join in or begin their own activity.
- Seeking and gathering space – People within the day service appeared to be jostling for space as they accommodated the different schedules and activities. This often appeared a priority for support workers as they sought to organise space through verbal direction.

- Staff explaining and discussing inhabitants – Support workers and managers were seen to frequently and openly talk about inhabitants, sharing past stories, discussing what they do and informing of things to look out for.
- Responding to time structure – Although support workers and inhabitants had different schedules according to their activities or responsibilities, the temporal structure of the day service (referring to its start, end, break and lunch) created generalised activity and movement.
- The community – Evidence involving the gathering of people, the distinct characters, the talk of the past and the social atmosphere of the hall created a feeling of a group of which one was either in or out (conversations with support workers suggested I was allowed to temporarily join as a former support worker, but that my position as a researcher caused them concern (ethno notes, 10th April)).

5.17 *Sociality*

The social aspect of everyday life that was eminent during analysis led me to return to the work of Gurwitsch (1979), specifically 'Human Encounters', and a commentator of this, Chelstrom (2016). In this text, Gurwitsch (1979) examines the ways that people come together in everyday circumstances, referring to three modes termed partnerships, memberships and fusions. Partnerships are concerned with the shaping of a person's role as prescribed through temporary, shared day-to-day situations (Chelstrom, 2016, p. 250; Gurwitsch, 1979, p. 104), so to return to the example of buying a coffee, the till person and I both assume roles and act in anticipation of the other – we trust each other through a collective intention (Chelstrom, 2016, p. 260). Memberships occur when people share backgrounds, traditions and ways of attributing value in taken-for-granted ways and cannot be left as in partnerships, for example being a member of a family sticks with one even if there is an attempt to abandon it (Chelstrom, 2016, p. 251; Gurwitsch, 1979, p. 126). Finally, fusions transform peoples' orientation toward the world and involves a deep-seated, mutual care and consideration in which differences are neutralised, such as that found between life-long partners (Gurwitsch, 1979, p. 216). Although the concepts of partnerships and memberships appeared to relate the units of meaning - the former through the transient ways support workers would participate in inhabitants' hobbies and interests, the latter through the sense of community membership and how groups acted together – at this stage they seemed too prescriptive to create new methods with which to explore the phenomenon, restricting my perspective of it rather than opening its possibilities. I felt that if these modes of being together were significant to the ways staff and

inhabitants shared everyday life, evidence of their particularities in this context would be strengthened and articulated through the second stage of data collection and analysis.

A further take on the phenomenology of social life in everyday life is given by the previously mentioned Seamon (1979) who expands on his concepts of body ballets and time-space routines to describe 'place ballet', where peoples' body-subjects and feeling-subjects become attuned with one another's through shared spatial and temporal contexts. If for example one visits a café each Tuesday during lunch, over the course of time one may become attuned to others that share in that space at that time – a person that regularly sits in a particular spot may bring a sense of assurance while their absence may feel strange. This appeared relevant to the spatial and temporal aspects that were identified in analysis and that were linked closely to sociality at the day service, namely how people appeared to gather at particular times in particular spaces despite pursuing their own projects. Further to this, analysis of the lifeworld data set had suggested that these concepts appeared relevant to Ben's experience of everyday life. At this stage however, Seamon's assertion that place ballet is 'unintentional and only comes about through time and many repeated "accidental" meetings' (Seamon, 2002, p. 45) dissuaded me from thinking of it as relating to everyday life at the day service as I considered it to be a phenomenon involving a great deal of organisation – the planning of activities, the intentional gathering of people (inhabitants and staff), the instructed ways for support workers to engage with inhabitants, and the fixed temporal schedule (three activity sessions and a lunch and a break).

Although this stage of analysis had not generated any particular methods with which to take into the second fieldwork period, it had highlighted social, project, temporal and spatial aspects of the everyday life that appeared to have some significance. Particularly, the units of meaning had suggested that of importance were the ways that people at the day service came together – through hobbies, responsibilities, community, and spatial and temporal dimensions – and this had felt relevant though unspecific to the theory that I had explored. The ethnographic method implemented in the first stage would be suitable to further explore this, though with an added focus on the social features of everyday life. As Atkinson (2014, p. 35) notes, 'we make a preliminary assessment of a given field and spend an initial period of time there. On the basis of those initial observations, we derive some preliminary working ideas. From those preliminary ideas we start to identify more cases and possibilities in the developing data, and our data collection is guided by those developing ideas'.

5.18 Stage 2 – Fieldwork methods

The second stage involved six days (8.50 a.m. – 3 p.m.) of fieldwork across three weeks. As discussed, this involved the same general methods used in the first stage – participatory observation involving note taking and ‘hanging out’ - though with a more refined focus guided by the aforementioned analysis. The support worker co-researcher also continued to utilise a participatory observation note taking method, making entries on four occasions. Another method that had been planned prior to the research, featured within the ethics applications and discussed with Ben’s family during the consent process, was an audio recording of his annual support review meeting. This involved his mother and step-father, a manager and a support worker from the day service, and a manager, a support worker and a behaviour co-ordinator from the service that provides support at Ben’s home. The purpose of this meeting is for the significant people involved in Ben’s support to discuss various aspects of his life over the previous year in order to think about and plan for his future. I wanted to capture this as I believed that an understanding of the events that Ben had participated in across a larger time period could help me to assess whether or not what I was observing were typical examples of his day-to-day experiences at the day service. It was also anticipated that the discussion could provide evidence that supported or questioned the developing interpretations of Ben’s experiences, allowing me to ask how my understanding of his communication and actions in situations may have been different to others, and if so, whether I needed to revisit these situations to ‘check with the participants that the experience was ‘captured’ accurately’ (Hodge, 2008, p. 31). I would argue that although lifeworld research is primarily concerned with in the moment, preconscious experience (Ashworth, 2016, p. 20), certain fractions of the lifeworld, temporality for instance, can be better examined through an engagement with a person’s biographical account, and that in the case of Ben, this was one way to access it in relation to day support services. A final benefit of audio recording the meeting was the possibility that it could offer insight into the phenomenon of everyday life at the service from the comments made by the service manager and support worker. This was an extension to my hanging out at the day service.

I organised the audio recording through a day service manager who subsequently contacted the service that provided support at Ben’s home. I liaised with these over email and provided information and consent forms, offering to answer any questions. These were signed before the meeting started. After introductions had been made and the recording had begun, I informed the attendees that although I would make some notes during the meeting, I did not intend to make any contributions though I was happy to answer any questions once it had finished. This was to allow the discussion to proceed as

naturally as possible despite the intrusion of myself and the recording equipment. Subsequently, the meeting was transcribed verbatim and added as a data source in Nvivo.

5.19 Stage 2 – Lifeworld Analysis

After I had left the field for the second time, I returned to analyse the data through the previously described process: the transcribed data was assigned into two sets – that of Ben’s lifeworld and that of the phenomenon of everyday life at the day service – of which I begun with the former, reading through and lingering with it before using Nvivo to code words, phrases and passages to the relevant fractions. I then closely examined each fraction, again assessing words, phrases and passages for units of meaning by asking of them:

- In relation to this fraction, how is Ben experiencing the situation?

Once I had examined the data set and assigned units of meaning, I considered the findings alongside those that arose in the initial stage. It became apparent that there were many similar ideas identified in the data, specifically in relation to Ben’s experience of space and time, though they were perhaps identified more acutely. If one takes for example the ‘expectation of order’ unit that had been identified in the initial stage, one also saw this appear in the second but alongside ‘focus on next step of schedule’ and ‘bodily sense of time’, suggesting that the focus instilled in the methods through the first stage analysis and phenomenology exploration had opened up some of the complexities of Ben’s experiences. These ideas also illuminated other areas of the lifeworld that had appeared weaker in the first analytic stage, ‘bodily sense of time’ for example suggested ways that the embodiment fraction of Ben’s lifeworld might be understood. Through this process, I came to the conclusion that each fraction of the lifeworld had been investigated, considered and investigated again, and that therefore the complexities of Ben’s lifeworld in relation to the study phenomenon had broadly been explored and could be explicated through a more detailed analysis. Fieldwork with Ben therefore came to a halt, though that is not to say that I would not need to return researching with Ben for further analysis could open up new avenues or ideas that required closer inspection. The support worker co-researcher was thanked for their efforts. The focus now became on understanding the phenomenon of everyday life within day services.

5.20 Stage 2 - Analysis of the phenomenon of everyday life at day support services

Once again I followed the analytic process described above. To look for units of meaning here I asked:

- In relation to this fraction, what does this situation suggest about everyday life at the day service?

The units of meaning that arose as a result of this analysis were very similar to those from the first stage analysis yet unlike that of the lifeworld analysis, they were not expanded upon with further units. At this point however I had a closer reading of Ben's experience of the phenomenon that could help me explore its interrelation with the study context. That is, I could consider how Ben's experiences may be similar or different to others that share the day support service, and this might suggest something about the phenomenon in general. To do this, I considered all the units of meaning that had arisen from both data sets. Units of meaning relating to the fractions of temporality, spatiality, sociality and project appeared most common. These ideas coalesced around the day service as a space in which people shared individual, daily routines. I had originally conceived of this as having its roots in the organisational structure of the day service in that support workers and inhabitants were abiding by the instruction inherent in its temporal and spatial planning (e.g. they arrived at a particular point and followed an intended plan as set out by the inhabitants' support plans). However, there was evidence in the units of meaning of both sets of data that the activity, movement and actions of people was not as scripted as I had thought, support workers for example appeared to frequently be attempting to orientate themselves towards what they or others needed to be doing, while the use of space was continuously shifting and being repurposed at different points of the day. For this reason I returned to the work of David Seamon and his concept of place ballet which I had previously disregarded due to his assertion that it is 'unintentional and only comes about through time and many repeated "accidental" meetings' (Seamon, 2002, p. 45).

To reiterate, place ballet is the meeting of individual time-space routines that over the course of time instils a pre-conscious familiarity in its participants (Seamon, 1979, p. 57). People are not necessarily aware of their position within the wider whole but may experience some disturbance if aspects of these routines were to change as it would necessarily change theirs in some regard. Routine here does not just refer to an order of activity and its related people, but to the customs, practices, actions and procedures relevant to a spatial and temporal context and its related people. The analysis suggested that although support workers and inhabitants did have some specific plans to follow, there were aspects of daily life that happened regularly though garnered little attention. For instance, support workers frequently talked about inhabitants – what they were doing, what they had been doing, who they were, what they were

like – yet there was no evidence of them being asked to do this, it just happened. Similarly, particular areas of the day service appeared to be left clear for inhabitants at particular times, Ben for instance usually arrived and took a spot at table close to his locker though I rarely saw anyone instructing others to clear this space, it was just available. As mentioned previously, these situations did not alone appear significant but when considered alongside each other suggested that closer investigation of the spatial-temporal patterns could help to explain the phenomenon of daily life at the service.

The ethnographic hanging out method in which I had recorded life at the day service through observations and note taking was, I thought, insufficient for the task of capturing its spatial and temporal patterns. Due to the hectic nature of the service, it was essentially too difficult for me to write down the comings and goings of support workers and inhabitants, their activity, communications and any other occurring events, as well as the related spatial and temporal contexts. Elsewhere (van Eck & Pijpers, 2017), place ballet has in part been researched through the use of fieldmaps which, when coupled with a participatory observation approach, has documented the shared experiential routines of a group of older people in a local park. I anticipated that this method could be useful in the context of the day service as it would allow me to record the same sort of notes that I had previously captured but position them on to a fieldmap and in doing so assign them spatial and temporal properties. This appeared to be a practical and appropriate way to more closely examine the phenomenon of everyday life at day services, as based on the findings of the first two stages, and therefore this method was adopted for the third stage of fieldwork.

5.21 Stage 3 – Fieldwork methods

To adapt the fieldmap method that van Eck and Pijpers (2017) had used, I created a floor plan of the day service ground floor (see below, Figure 4). There are other floors to this building however these are generally used by individual inhabitant-support worker dyads and they therefore did not appear as relevant to the shared experience of everyday life.

The first two stages had shown that daily life fluctuated around morning and lunch periods, when support workers and inhabitants arrived, gathered and departed; at other times, people were pursuing their individual schedules, such as when Ben visited the gym. Consequently, I decided to conduct data collection during the following periods: Monday 8.50 a.m. – 10.20 a.m.; Tuesday 11.40 a.m. – 13.20 p.m.; and, Wednesday 8.50 a.m. – 10.20 a.m. In order to record events across these time periods, I began a new fieldmap every 10 minutes, occasionally moving my position in an attempt to ensure I was not missing

anything significant. I collected data on four occasions for each day and so, in total, I documented events on 120 fieldmaps, scanning them into an electronic format subsequent to each day of fieldwork before uploading them to Nvivo.

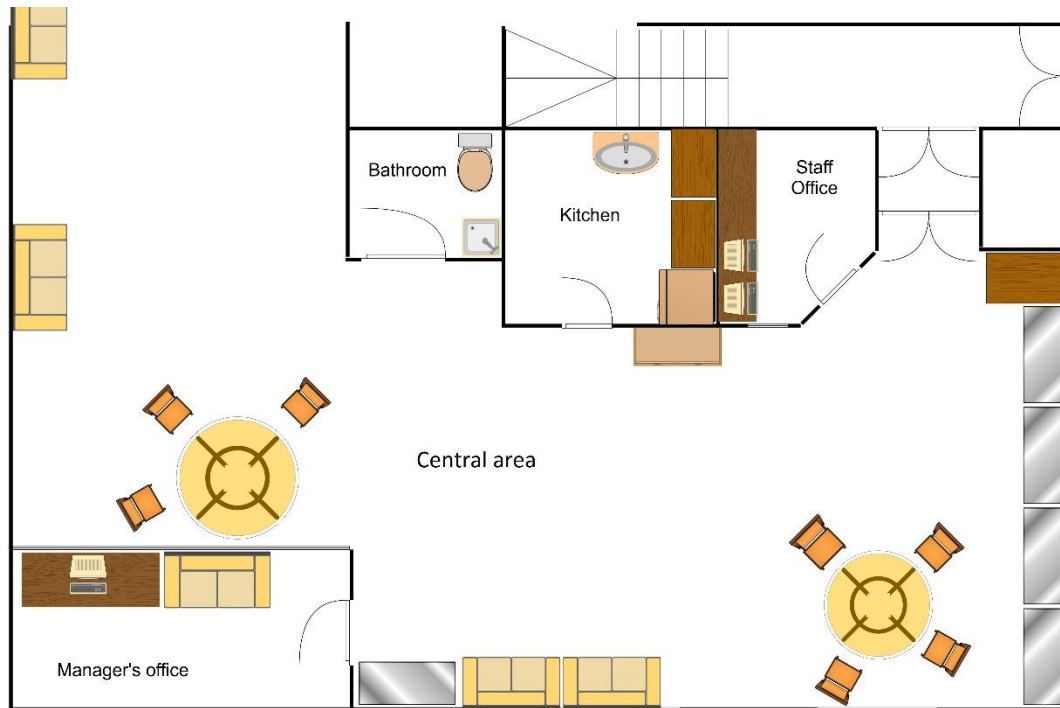


Figure 4: 'The Hall' Fieldmap example

The area depicted in the fieldmap is what service staff refer to as The Hall. It consists of a central area that is surrounded by smaller rooms. There are two tables with seats, further seating along its sides and on the far right, a row of lockers for inhabitants. The primary way to enter the Hall from outside is via the three sets of doors on the top right of the fieldmap, though people occasionally use a further door in a room, low lit for an inhabitant, that is located 20 yards past the bathroom on the left side. The staff office is where support workers complete computer and paper work though inhabitants also occasionally use it for activities or dining. The kitchen - used for making lunch and drinks – has a lock on that support workers have a key for though it is sometimes left unlocked. The manager's office has a glass wall that provides visibility both in and out while the usually open door means that it is regularly frequented by staff and inhabitants when seeking the manager or their deputy. If I refer to the Hall within this thesis, I am referring to the space as a whole – essentially the ground floor of the serving building - that includes the areas shown on the fieldmap as well as the previously mentioned darkened room. I decided not to include the low lit room on the fieldmap as it would have diminished its available space, hindering my ability to write notes where most people gathered; however, I did use the top left corner when there were

occasions of interest from that area though it should be said that the room was generally only used by one inhabitant and their respective support worker. Specific areas will be referred to as they are labelled on the above fieldmap.

This is an example of a completed fieldmap:

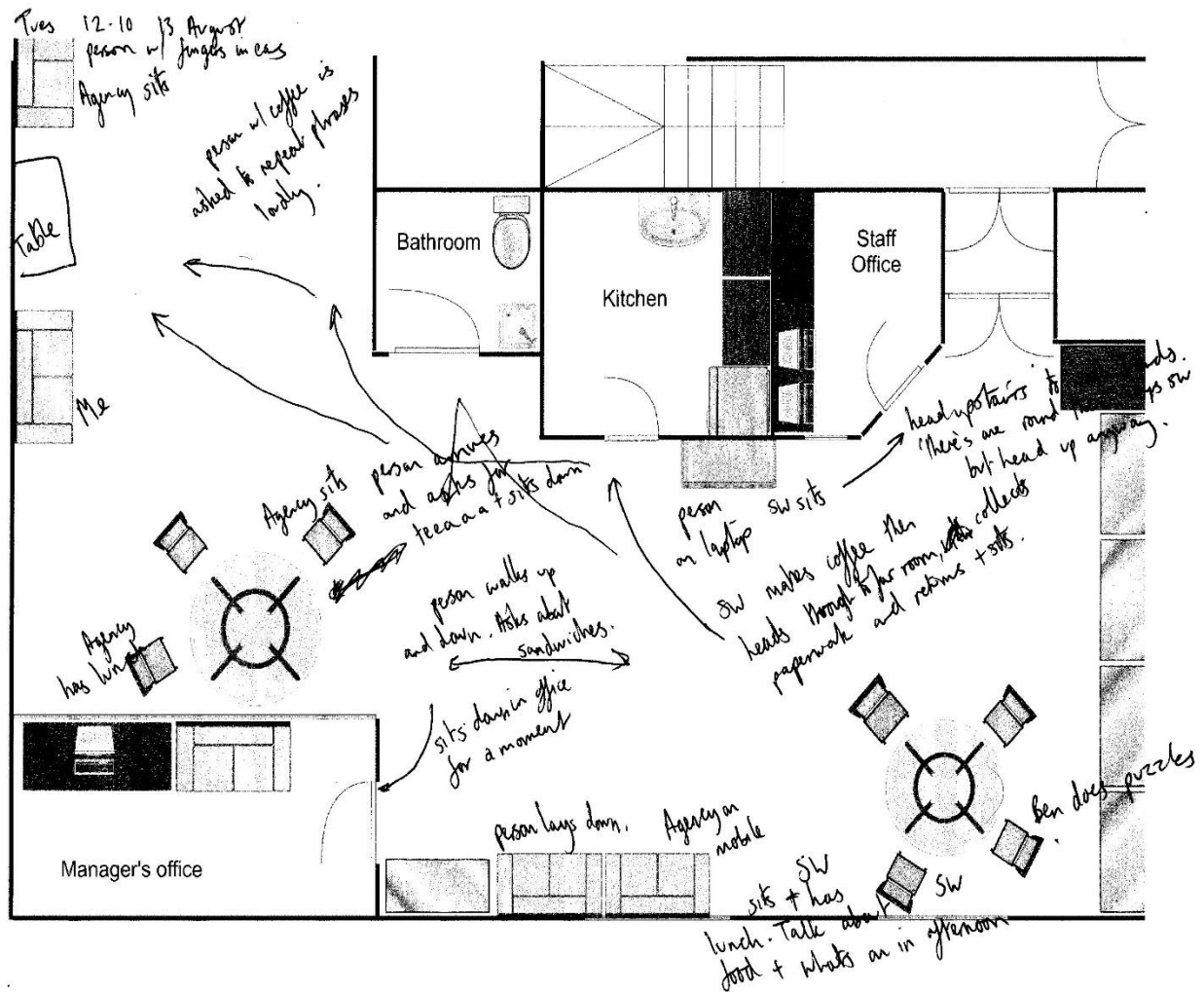


Figure 5: Example of completed fieldmap

After documenting fieldmaps for four weeks, I left the field for the final time though, as mentioned, I was prepared to resume fieldwork if analysis showed aspects of the phenomenon needed further investigation. The day service were informed and kindly told me that if necessary, further fieldwork would not be a problem.

5.22 Fieldwork Summary

I have presented the three stages of fieldwork that were guided by the process of thinking phenomenologically while doing phenomenology (Berndtsson et al., 2007). Here is a brief summary:

Stage 1:

Methods:

Approach - participatory observation, ethnographic hanging out. 9 days of fieldwork (8.50 a.m. – 3 p.m.)

Method - note-taking (Simmons & Watson, 2014b, pp. 155-156), support worker co-researcher note-taking.

Analysis of Ben's lifeworld:

Temporality and Spatiality – explored Seamon (1979), Kwan (2017) and Heidegger (1962). Stage 2 focus on anticipation of events, planning, direction and routines.

Sociality, Selfhood and Project – explored Gurwitsch (1962) and Schutz (1976). Stage 2 focus on differences and similarities in interactions between Ben and support workers, explore their knowledge of one another.

Analysis of everyday life as a phenomenon:

Sociality (as related to project, spatiality and temporality) – explored Gurwitsch (1979), Chelstrom (2016) and Seamon (1979). No specific focus generated, though a tentative idea relating to the ways in which people came together.

Stage 2:

Methods:

Approach - participatory observation, ethnographic hanging out. 6 days of fieldwork (8.50 a.m. – 3 p.m.)

Method – refocused note-taking, support worker co-researcher note-taking, audio recording of annual meeting.

Analysis of Ben's lifeworld:

All fractions appeared illuminated to greater or lesser extents. Fieldwork halted.

Analysis of everyday life as a phenomenon:

Spatiality, temporality and sociality – place ballet of Seamon (1979) appeared relevant once data had been assessed as a whole. Directed towards a focus on routine of everyday life through fieldmaps.

Stage 3:

Methods:

Approach - participatory observation, ethnographic hanging out. 16 days of fieldwork.

Method – fieldmaps, note-taking.

Left field.

5.23 Reflecting on trustworthiness

First proposed by Lincoln and Guba (1985), trustworthiness is a common model used to evaluate the quality or rigor of qualitative research, and uses the criteria of credibility, transferability, dependability, and confirmability. Here, this criteria, as elaborated on by Thomas and Magilvy (2011) and Cope (2014) will be used to reflect on the trustworthiness of the study outlined in this chapter. Credibility refers to the whether the data accurately reflects participants' experiences, and whether others in similar circumstances would recognise these experiences (Cope, 2014). Member checking is a common method used to establish credibility, involving a researcher returning to participants after data collection and asking them if interpretations of their experiences are accurate. This study's multi-stage design provided one way to member check, as, after periods of analysis, I returned to Ben and the day service on multiple occasions to question and explore whether my understanding of his experiences were reflected in what he was communicating. This circular process of fieldwork, analysis, fieldwork, and so on, is, I argue, a novel and important way to member check when working with autistic people with profound learning disabilities, and is supported in this chapter through the detailed notes of how I returned to Ben with ideas on, and analysis of, his experiences, and how these were accepted or challenged through further engagement. The design also supports the study's credibility through its use of persistent observations, which as Cope (2014, p. 90) suggests, brings depth to the data, while the prolonged engagement at the day service, and multiple methods used, adds scope to the data. These two approaches resulted in data that showed ways in which Ben's experiences relate to other inhabitants at the day service, as detailed in Chapter Six, Part Two, thus suggesting that the described experiences would be recognised by others that share the same experience.

Transferability refers to whether findings may relate to other settings and other groups (Thomas & Magilvy, 2011). As mentioned above, the study's approach resulted in thick descriptions of the day service context, which informs as to how this day service may relate to others. The way in which Ben accessed the day service and the central importance of the main gathering space, 'The Hall', suggests that the study would relate to other day service provision with a focus on a community space, as opposed to provision that focuses on outreach or home support. The fieldmaps method, for example, is likely not an appropriate method to investigate the culture of a service which provides support without a base, on an individual basis in community settings. Transferability may be apparent though in the types of relationships and interactions Ben was observed as having with support workers and peers, as these were observed on a prolonged basis, in many different circumstances, both in and out of the services. The broader observations of everyday life at the service also showed similarities between the relationships

Ben had with his support workers, and those his peers had with support workers. On this aspect of the study then, the findings and observational methods may be transferable to other settings where autistic people with profound learning disabilities engage with support workers. This is important as these interactions were indicative of how autistic people with profound learning disabilities contribute to service culture, and thus may be seen across other support service contexts.

Dependability refers to the transparency of a researcher's decision making throughout a study. An important aspect of this is how and why participants are selected for a study, and how and why particular methods are implemented (Thomas & Magilvy, 2011, p. 153), both of which were addressed through a significant portion of this thesis as it explored the question of 'autism and profound learning disability' (Chapters Three and Four). The exploration of autism and profound learning disability goes beyond what would generally be asked of a researcher in clarifying how and why their participants were chosen, though it may also serve as a tool with which to question other studies which focus on people with complex needs only in relation to 'autism', or only in relation to 'severe or profound learning disabilities'. This also relates to the aforementioned criteria of transferability, as the arguments put forward in the third and fourth chapters support a case that the study's findings and methods are, to greater or lesser extents, transferrable to other persons who share the life conditions relating to the space of autism and profound learning disability (see Chapter Four part one); namely, people with complex needs who are considered autistic, and/or with severe or profound learning disabilities. Dependability in this study has also been addressed within this chapter, through the detail given on how fieldwork and analysis stages developed over the course of the research, including reflection on decision making processes and reasons why other approaches were not chosen. Furthermore, the multi-stage design gave ample opportunities to establish dependability by sharing and reflecting on on-going findings with my study supervisors, as Cope (2014, p. 89) recommends.

A study's confirmability can be established only after its transferability, dependability and credibility are considered (Thomas & Magilvy, 2011), and requires the researcher to be reflexive and reflective, with reference to how they were involved in its processes, and how they may have influenced its direction. In part, reflection and reflexivity are given within this chapter, as part of the process of describing how interpretations of the data came about. This is further supported below, through the description of the final analysis period, as well as in the data extracts given in the findings chapter. Finally, Chapter eight serves as a reflective discussion on the methodological approach and how it practically allowed participants to be involved across study processes.

5.24 Methods - Analysis

Analysis of lifeworld data does not follow any predefined process as the method should be appropriate to the phenomenon and the persons that experience it (Finlay & Molano-Fisher, 2008, p. 258). Narrative analysis for example was used by Öhlen (2003) as they encountered people in palliative care sharing their experiences through narrative dialogues. The aim of my analysis was two-fold: to make sense of the phenomenon of everyday life at day support services, and to explore the particular experiences of this phenomenon from the lifeworld perspective of Ben. To do this, I used a theoretical thematic analysis as described by Braun and Clarke (2006). Thematic analysis is a qualitative analytic method for locating and analysing themes within data. It follows a six phase process that enables the organisation and rich description of data as a whole (a set) (Braun & Clarke, 2006, p. 79). Thematic analysis is not concerned with any particular theoretical framework and can thus be used with theoretical frameworks, such as that of lifeworld fractions, or as an inductive approach in which themes are identified from the data alone (Braun & Clarke, 2006, p. 83). In the case of this study, the prior fieldwork process had identified relevant theoretical frameworks to aid investigation of the research questions. However, as Braun and Clarke (2006, p. 80) assert, it is important to acknowledge the theoretical underpinnings of the related theories to demonstrate how they are appropriate to the study questions and its wider methodological approach. Although lifeworld fractions (Ashworth, 2016) and place ballet (Seamon, 1979) are both rooted in phenomenology and the concept of the lifeworld, their origins lay in two different schools, the former being that of Husserl (1970b) and description, the latter being that of Heidegger (1962) and interpretation. I have addressed these concepts in the methodology chapter but, in order to justify my analytic approach, I will provide a brief explanation of them in relation to these theoretical frameworks and the study questions.

- The descriptive approach that underpins lifeworld fractions is concerned with the 'lived-through meaning of an experience' (Ashworth, 2016, p. 21) and so adopts the previously described epochē to enable the researcher to get at the experience as it is to the participant. It stays distinctly with the experience of an object or event (the phenomenon) and does not concern itself with the wider context or relevant theory (Lopez & Willis, 2004, p. 727), though the fractions cannot but appear as they are inevitably felt in any experience (Ashworth, 2016, p. 23). For this reason, lifeworld fractions and its descriptive underpinnings were appropriate for aiding investigation into the question of how Ben experienced everyday life at the day service.

- The tenets of interpretation (hermeneutics) lay in the complex integration of life and world and so research in this tradition looks for ‘meanings embedded in common life practices’ (Lopez & Willis, 2004, p. 727). The particular experiences of a person are enmeshed with their particular life conditions (Kraus, 2015, p. 2) and as such this requires investigation. When relevant, interpretative inquiry is open to the use of theory as a framework to examine evidence and therefore the concept of place ballet – rooted in the hermeneutic tradition and as identified through the fieldwork process - was considered as meaningful to the study context. Examining the evidence through this concept and its related framework was thus appropriate for the analysis concerned with phenomenon of everyday life at the day service.

These approaches are not mutually exclusive, their related ‘scholars embrace a continuum’ (Finlay, 2011, p. 136) and so while Ashworth is dedicated to the descriptive tradition, he states that ‘interpretation is justifiable if the research plainly remains within the phenomenological realm, that is, the realm of experience’ (Ashworth, 2016, p. 22). In using fractions and place ballet to analyse data, I am positioning myself on this continuum toward the interpretive tradition, acknowledging the value of description to elucidate the meaning of Ben’s experiences while accepting that this embedded in the conditions of his everyday life. It is true though that these theoretical frameworks require different analytic methods, fractions concerning the epochē while place ballet concerning reflexivity, and this process will be discussed where appropriate.

A further requirement of thematic analysis is to situate it within an epistemological paradigm as this informs how one views, conceptualises and reports on data, and, as in this case, this is particularly important if a study focus has developed since conception (Braun & Clarke, 2006, p. 85). In line with the research as a whole, the epistemological assumptions of this analytic approach are a constructionist, subjectivist epistemology and a critical realist ontology. The analysis is appropriate therefore as it addresses the subjective lifeworld experiences of Ben while also accepting that this is contextualised in the life conditions of the day service and its related day-to-day events, the study phenomenon. This is a reaffirmation of the study’s interpretative grounding.

To organise data, I created two data sets, one relating to Ben’s lifeworld experiences, and another relating to everyday life at the day service more broadly. These data sets were sourced from any data collected during fieldwork, including observational notes, fieldmaps, archive documents, an audio recording of Ben’s annual service review meeting, and the observational notes recorded by the participant co-researcher. In amalgamating the participant co-researcher’s notes into the wider data, it can be said

that the constructivist stance of the study was disturbed, marking instead a constructionist process. While this was not the original intention, the amount of data that the co-researcher had collected was not sufficient to analyse alone, as a single data set. It was also the case that they would not be involved in the analysis due to related time constraints, and so it was my own understanding of their perspective, as recorded in their observations, that led the analytic process. In style, the participant co-researcher's descriptions of Ben were less vivid than my own, tending instead to involve quite literal descriptions of events and interactions. These differences may relate to the disparities in methods training, and their notes may have been different if provided with a more significant period to practice, prior to fieldwork. It was also the case though, that as part of the attempt at constructivism, I wanted the co-researcher to observe and write as they saw and understood Ben, not as I did, so it was to be expected that their perspective would be different to mine. Indeed, the more literal descriptions related closely to how support workers write about those people they support as part of their day-to-day responsibilities, so it could be argued that their notes reflected their position and perspective as a support worker.

The questions I asked of the data sets concerned the second and third objectives of the study: that is, to explore the day service experiences of an autistic person with profound learning disabilities, so that these can be related to the service culture that they are part of. And, to investigate the role of the everyday within day service culture. Thus, I asked:

In regards to the data set concerning Ben's lifeworld:

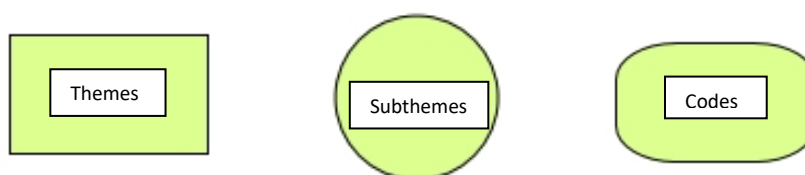
- *How does Ben experience everyday life at day support services?*

In regards to the data set concerning the everyday:

- *What characterises everyday life at day support services as a phenomenon?*

Concept Maps

Throughout the analysis, I created concept maps to explore the relationships between themes, subthemes and codes. These evolved over time and through different stages of analysis, creating new subthemes and themes and eventually illustrating the final analysis. Within these maps, I represented themes with rectangles, subthemes with circles and codes with soft-cornered rectangles:



5.25 Methods - Analysis of Ben's experience of everyday life at day support services

As mentioned, Braun and Clarke (2006) provide a six phase process with which to thematically analyse data sets. The first two are similar to the lifeworld analytic method as described by Andrews et al. (2019) and used during the fieldwork analytic stages. First, I familiarised myself with the data and this meant re-reading all data that I and the support worker co-researcher had collected during the fieldwork stages, lingering with it by thinking about the possibilities of what it may mean for Ben (Finlay & Molano-Fisher, 2008, p. 258), before re-reading it again. In the second step I coded the data using Nvivo, employing the fractions to identify units of meaning. At this point it was important to follow Ashworth (2016, p. 21) and instigate the epochē. I examined the data and asked of words, phrases or passages: in relation to this fraction (e.g. temporality, embodiment, etc.), how is Ben experiencing this situation? I also did this for the fieldmaps from the final stage of fieldwork, instead highlighting areas of fieldmaps that suggested ways Ben was experiencing a situation and coding it to a unit of meaning. In the below example, I identified a situation in which Ben was surrounded by busy activity yet remained quite still (he didn't move for the full 10 minutes), observing in a way that demonstrated a directed interest toward the lives and pursuits of those he shared the Hall with (relating to sociality, moodedness and project) – I thus identified 'stillness in commotion' and 'showing interest in others' as units of meaning. Further to this, I knew through my acquaintance with the wider data set that this is where Ben sits every morning when arriving, suggesting some personal connection to this space at this time (relating to spatiality, selfhood and temporality) and assigned as the units of meaning 'creating own space' and 'reliving the past'.

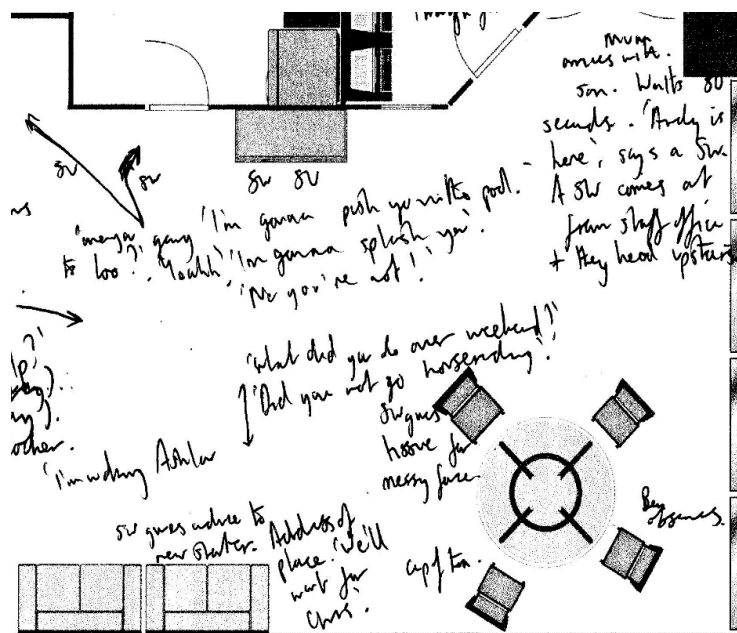


Figure 6: Fieldmap, 15th July, 9.40 a.m. Notes read:

'Ben observes'; "what did you do over weekend? Did you go horse riding?" SW gives tissue for messy face';

'SW gives advice to new starter. Address of place. "We'll wait for Chris";

'SW, SU, "I'm gonna push you into the pool" "I'm gonna splash you" "No you're not!";

'Mum arrives with Son. Waits 30 seconds. "Andy is here" says a SW. A SW comes out from staff office and they head upstairs'.

Once I had done this for all eight fractions across the entire data set, I had identified 61 units of meaning. The third phase concerns the search for themes across the identified units of meaning. To do this I looked for commonalities between units of meaning, grouping them together into 'theme-piles' (Braun & Clarke, 2006, p. 89) within Nvivo before considering further their relationships, whether there were potential subthemes and how well the units of meaning fitted into their related themes. Some units of meaning did not appear to fit into any themes and were left in a miscellaneous category. I show in the below example the theme 'Living the future through the past', its related subthemes (marked ST) and units of meaning. At the end of this process, I had identified four candidate themes: 'Living the future through the past', 'Feeling sensory environment', 'Minimising direct input' and 'Shifting identities'.

Name	Sources	Reference
Living the future through the past	0	0
Adhereing to others temporal schedules	3	9
learning of Ben through past	4	7
Reliving the past	15	28
sharer of routine and projects	31	60
ST fear in facing change	0	0
frustrated expression	8	11
negative vocal direction	9	13
schedule causes anxious cloud	6	6
ST Organising	0	0
bodily sense of time	4	5
Events to signify order	15	22
expression of personal space and activity	6	12
focus on next step of schedule	7	11
high fives to acknowledge and finished moment	11	22
others arranging space and time	32	57
routine and project in space	25	45
routine spreads across room	3	3
showing schedule to himself and others	16	43
speeding up between events	9	14
ST requires to live in time and space	0	0

Figure 7: Screenshot of candidate theme 'Living the future through the past' within Nvivo.

Phase four of analysis involves an in depth review and refinement of the candidate themes. Here I looked for coherence within and divergence between candidate themes by reading all the data contained within each theme and asking whether the extracts fitted in with my conception of the theme, as well as assessing whether these concepts were close to those found in other themes (Braun & Clarke, 2006, p. 91). I aided this process by writing about the themes, using data extracts to support or challenge my thinking. For example I found that the candidate theme of 'Minimising direct input' - in which I had found a relationship between units of meaning that suggested that Ben experienced a need to manage his support workers' direct communication – had many similarities to ideas I had identified in the candidate theme 'Feeling sensory environment', as well as aspects of 'Living the future through the past'. By expanding on what I was interpreting in the data at this local thematic level – in relation to individual themes as well as between themes – I found that the units of meaning identified in 'Minimising direct input' cohered more appropriately to the developing ideas within 'feeling sensory environment' and it thus became a subtheme there. This was aided through the use of thematic maps with which I visualised the developing themes - below is an example of the 'Feeling sensory environment' map at this stage. Subsequent to this, I returned to the entire data set, re-reading it again and assessing whether the candidate themes appeared coherent to it as a whole, asking for instance if they were contradicted in other areas. I also coded any data that was relevant to the candidate themes but that I had missed during earlier stages. My aim was to evaluate whether the candidate themes were beginning to address the related research question of how Ben experiences everyday life at day support services through the concept of the lifeworld, and when I felt that they were, I moved to phase five of analysis.

In the fifth phase I articulated and developed the candidate themes through further writing. This was a process in which I continuously returned to the data that I had identified in relation to each theme and asked what it said about how Ben was experiencing the situation. To do this from a lifeworld perspective, I had to orientate myself towards the experience as it was given to Ben pre-consciously. For example, in the above subtheme 'Minimising social input' is the unit of meaning 'high fives to acknowledge and finish moments' in which data shows Ben high fiving support workers when he had finished hobbies or other areas of his everyday schedule; here, I am not asking what Ben thinks about this moment, or why he is high fiving the support worker, but what is this experience like for Ben? So in this case, I thought that Ben was experiencing a support worker who needed guidance and a self that could provide it, and also that he experienced a moment that had finished and this suggested a temporal temporal schedule that he was drawn to. When considering this within the subtheme, one saw a pattern

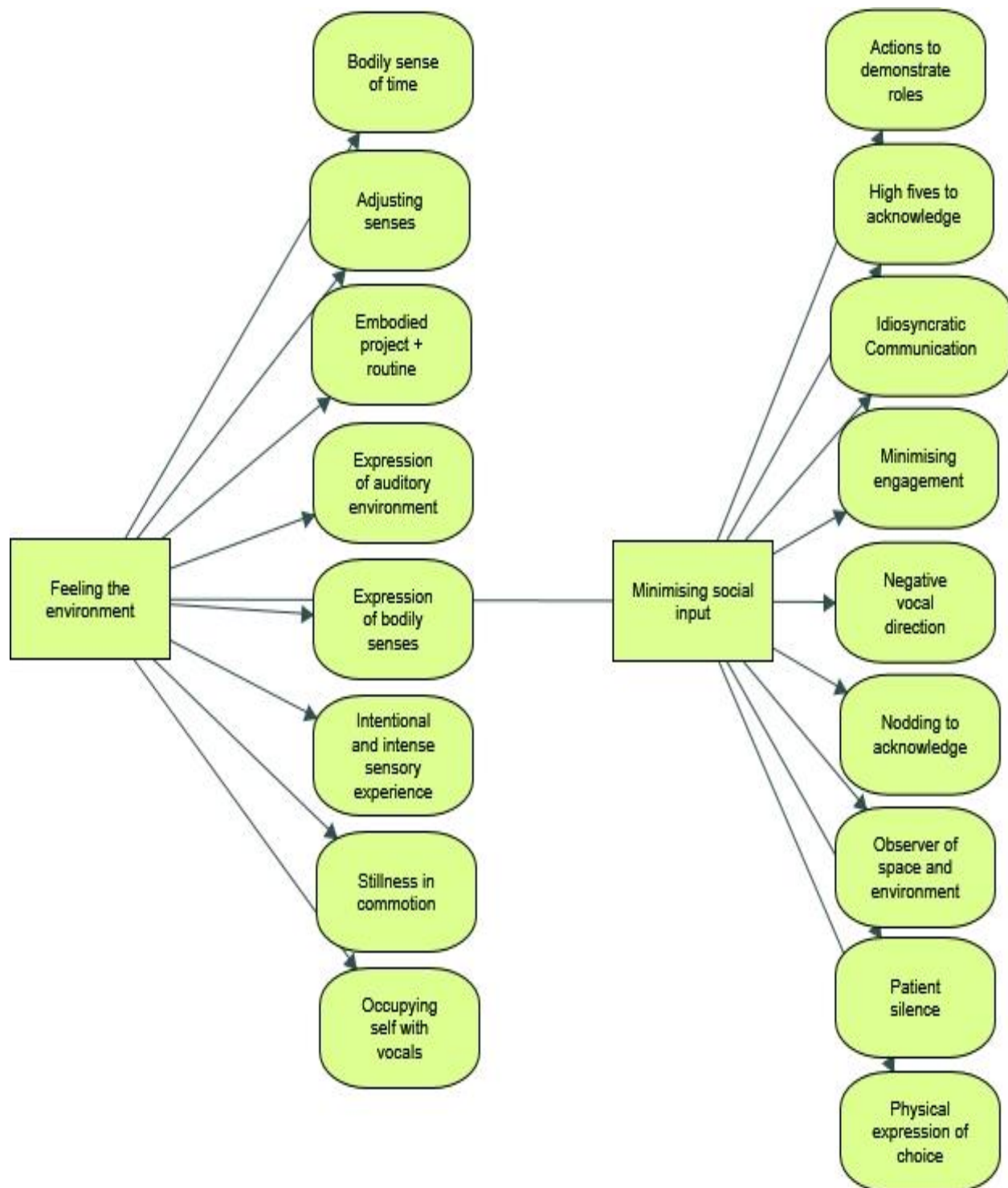


Figure 8: An example of a thematic map of the 'Feeling sensory environment' candidate theme during phase 4 of analysis.

across data that I had first thought about as Ben's experience as the manager of people's communication, yet by attending to and exploring the theme as a whole this became concerned with Ben guarding his

bodily experiences within the busy surroundings that he finds himself in – his lifeworld experience of everyday life. At the end of this phase, three themes were clearly identified, described in part and with supporting evidence, they were: ‘Living the future through the past’, ‘A Visceral World’ and ‘The Contextual Shifting of Identity’.

The final phase of analysis was concerned with fully describing and interpreting each theme while providing adequate and illuminating evidence to support their claims. This was shared and discussed with my supervisors as a way to question the interpretive process and to assess whether the analysis was addressing the research question.

5.26 Methods – Analysis of what characterises everyday life at day support services as a phenomenon

The same six phase process was also used to thematically analyse the data in relation to the phenomenon of everyday life at day support services. The theoretical scope for this was place ballet as defined by Seamon (1979). In using this I was making the assumption that, as based on the findings during the three stages of fieldwork, place ballet was an appropriate frame of reference to examine the phenomenon in this study context. Place ballet is the ‘coming together of people’s time space routines and body ballets in terms of space... its crux is the prereflective bodily regularity of routine users’. It is defined by Seamon (1979, pp. 143 - 152) as having six requisite characteristics that will be evident to greater or lesser extents depending on the circumstances of the place ballet, these are:

- **Attraction:** The attraction of a place through its potential activity. As it draws people, issues can arise in over-crowding or a lack of resources. This may create regular patterns of movement and events in which participants respond to the fluctuating attraction.
- **Diversity:** The potential variety of a place. Diversity in a place means that more people will be drawn to it as it satisfies a greater degree of interests and purposes. Once there, new interests will grow through the range of activity.
- **Comfortableness:** The place fosters comfort through its ease of use. This is felt physically and psychologically by its participants as they are able to pursue their interests with few interruptions. Those new to the place may not feel such comfort if its flow and movement are dissimilar to their usual patterns.

- **Distinctiveness:** The place appears as something distinguishable. It has a unique character that stems from the distinct mix of participants and activity. Their shared histories create original patterns of activity and habits that give a sense of place.
- **Invitation:** Successful place ballets will make new participants welcome. They invite them to be part of its activity and customs. This may relate to particular people over others; for some, the place may reject them and they will not want to return.
- **Attachment:** The connection that participants have with a place. They will demonstrate a care for it, instinctively seeking to maintain it for its related people. Places that do not foster attachment may find its participants as apathetic or even callous toward it.

When conducting this analysis, I implemented a reflexive engagement that sought to acknowledge how aspects of my perceptions and experiences may have guided my interpretation of the phenomenon (Finlay, 2011, pp. 113 - 114). To do this, I first attempted to situate my personal experiences of day service life as a support worker through reflective writing. I also grouped together reflective and reflexive notes that I had made during fieldwork using Nvivo in order to help understand my position within the research process. During the six phases of thematic analysis, I referred back to these articles and questioned the ways interpretation of the data was influenced by my position so as to help move past this understanding and see the phenomenon in new light.

This place ballet framework was applied in the second phase of analysis. So, after I had read and lingered with the data in accordance with the first phase of thematic analysis (Braun & Clarke, 2006, pp. 88 - 89), I examined the data and asked of words, phrases or passages: in relation to this place ballet characteristic (e.g. attraction or diversity), what does this situation suggest about everyday life at the day service? I utilised the same method when interrogating fieldmaps, examining sections and asking the same question. The result of this phase was 57 units of meaning.

Following the same analytic process as described when analysing Ben's experiences, in the third phase I grouped units of meaning through shared commonalities. I identified six candidate themes at this point: 'A community'; 'Rules of engagement'; 'A place to learn'; 'Sense of Risk'; 'Spatial Customs'; and 'The routine of daily life'. Reviewing these candidate themes in the fourth phase - looking for coherence and divergences, visualising them with theme maps and considering them in relation to the whole data set – they were amalgamated into the latter four candidate themes mentioned above. In the fifth phase I distinctly articulated these themes before a full interpretive description of each in the sixth phase.

5.27 *A Summary of the methods chapter*

This chapter has detailed the process of empirically investigating the everyday at a day service for autistic adults by using 'lifeworld fractions (Ashworth, 2016) to think phenomenologically while doing phenomenology (Berndtsson et al., 2007).' It began with a description of the steps taken to receive a favourable ethical opinion to conduct the research, before discussing the process of establishing a research site and recruiting participants. Introduced was Ben, a young autistic adult with profound learning disabilities, who attends the day service three days a week. Research was conducted with Ben to learn of his experiences of the everyday, and this happened during his day-to-day pursuits at the day service, through participatory observations from myself, and a support worker co-researcher. An ethnographic approach was also used to collect evidence of the phenomenon more broadly, as observed in the activity, talk and goings-on at the day service. Through the first two stages of fieldwork and analysis, the phenomenon of the everyday began to be understood from Ben's view, through theoretical perspectives highlighted as significant within relevant fractions, particularly in regards to aspects of space and time. This understanding prompted a new way to research the everyday, through a fieldmaps method that recorded the spatial and temporal dynamics of day service life, as observed within its main gathering space, the Hall. The result of this process was two data sets concerning the everyday within the day service, one that focused specifically on Ben's experiences, and another that concerned day-to-day life in the Hall. To conclude, the methods used to analyse both data sets was described.

In providing a detailed description of the methods involved in this study, with reference to the practical application of using lifeworld fractions to think phenomenologically while doing phenomenology, this chapter makes contributions that address both aims of this research. In relation to day service culture, it provides methods of researching service cultures that include the contributions and perspectives of inhabitants, particularly autistic people with profound learning disabilities. The chapter also describes and gives reasoning for the ethical considerations required when planning and conducting research in day service spaces, with particular emphasis on the participation and roles of autistic people with profound learning disabilities. One important point was that ethics committees may not have responded sufficiently to developments in qualitative research with autistic people with profound learning disabilities, causing them to have doubts about less predictable research approaches. Researchers can respond to this by anticipating the circumstances that may arise during research, even the less likely ones, and this can be aided through engagement with services, community members and practitioners in the field of autism and learning disability. In the case of this research, one way the risks were anticipated was through a prior understanding of the research context, including the inhabitants of the day service. The second aim of this

research was to develop a methodology with which to research phenomena through the experiences of autistic people with profound learning disabilities. This methodological development has, in this chapter, been given a practical grounding, through a description of its approach, including the multi-stage, cyclical process of fieldwork and analysis that was used to guide the research in line with Ben's experiences and relevant phenomenological theory. Ben contributed his perspective of everyday life through the ways he communicated, acted and interacted across the diverse situations at the day service, and in doing so, provided an understanding of the phenomenon that shaped the final stage of fieldwork.

Chapter Six – Findings

Part One – Ben’s Lifeworld

This chapter seeks to address the first aim of this study: to explore day service culture from the perspectives of autistic people with profound learning disabilities. Due to the complexities of accessing the perspectives of people from this group, the second and third objectives were established. The second was to ‘explore the day service experiences of an autistic person with profound learning disabilities, so that these can be related to the service culture that they are part of’. The purpose of this objective was to give an in depth account of how an autistic person with profound learning disabilities experiences, shapes, contributes to, and is guided by, cultural practices and customs within a day service. As it was suggested in the first part of the literature review (Chapter 2.5), these experiences and contributions take place in the everyday, while it was argued in the methodology chapter that a lifeworld approach was the most ethically sensitive way of sourcing and understanding this perspective. The first part of this chapter’s finding therefore focuses on the lifeworld of Ben, as relating to his experiences of everyday life at the day service he attends. This is a detailed analysis of Ben’s subjective lifeworld perspective, described and illustrated through any data that was collected concerning his experiences: fieldnotes (that of mine and the support worker co-researcher), transcribed audio recordings and fieldmaps.

While the first part of the chapter provides understandings of service culture from the specific perspective of one person, Ben, the second part looks to meet the third objective and contextualise these within the wider context of day service life. To do this, it looks at the broader cultural customs that dictated everyday life at the day service that Ben attends. As an inhabitant at the day service, Ben was often part of these customs, though here the findings also relate to how other inhabitants, as well as members of staff, contribute and experience culture. It focuses on the main gathering space at Ben’s day service, ‘The Hall’, as it was established during fieldwork as a site important to everyday life, through the way activities, events and practices were organised around it. The Hall was viewed in relation to space and time, through the scope of place ballet (described in Chapter 4.24), as these were understood as significant elements of Ben’s lifeworld perspective, indicating that it was also a scope which could include the contributions and perspectives of other autistic people with profound learning disabilities, as well as the broader community at the day service.

Within the first part of this chapter, there are three central themes described in relation to Ben’s lifeworld: first, ‘The contextual shifting of identity’ describes Ben’s experience of himself and others across the different circumstances and contexts of the day service. ‘A visceral world’ then details Ben’s embodied

experiences in the environments, activities and social situations of everyday life. Finally, 'Living the future through the past' shows the significance of Ben's temporal and spatial experiences in day-to-day life with reference to the safety and security of his past.

To note: all names in data extracts are pseudonyms.

6.1 The contextual shifting of identity

An inevitable aspect of Ben's position as an inhabitant of the Hall is that his day-to-day experience of himself and others is through the circumstantial lens of support. Ben finds himself in interchanging dyadic relationships with support workers that exist through the initial conception that he requires some kind of assistance. He cannot escape this, yet these dyads are more complex than one person assisting another and involve him and his support workers assuming different roles as they come to know one another. In the following section, I will explore how four aspects of Ben's identity – termed the supported, the supporter, the independent and the partner - gain prominence through the varying social experiences of everyday contexts.

6.2 The Supported

Katie who is supporting Ben sits down next to me... She mentions she has only done the session (going to the gym) once before and she thinks Ben knows most of what to do himself... As I had been along with Ben the previous two weeks, she asks questions about what happens – whether he still goes for a drink afterwards and if he still likes to go on a particular machine (ethno notes, 15th April).

A support worker meeting Ben for the first time draws from his service file, observations of Ben in the Hall and conversation with colleagues to form a concept of who he is and what they need to do. There are specific ways of acting and engaging with Ben, instructions on what he can do and how support workers can ask him to do it – '(he)... can use his bus pass: prompt him to place it on the scanner by the driver and wat (sic) until it has registered' (gym activity plan, Sep 18). Although this may differ from support worker to support worker depending on how the information is learned or remembered, or their experience of support work and other such factors, on the whole support workers will engage with him throughout the day based on this ever repeating, prescribed mode of interaction. Over time, this has made Ben the expert in these dyadic relationships, knowing and expecting the order and manner of interaction, waiting for support workers to fulfil their roles through the actions that have come before, such as when he arrives in the mornings:

Ben arrives and puts his bag and coat in his bag and sits down at the same table as the previous day. A support worker brings out two bottles of squash from the kitchen and he chooses apple by tapping it. He puts his fingers in his ears and smiles slightly until the drink is bought out (lifeworld notes, 2nd April).

The above example details the interaction that happens every morning as a support worker asks Ben if he would like a drink by presenting him with two bottles of squash, to which he picks one or turns his head away to indicate a no. In these moments, Ben's position as a 'service user' effects his support worker into going to the kitchen, offering the bottles and then making him a drink if requested. His experience is primarily one of privilege within the dyad: he sits and they provide for him without question, though lunch time observations demonstrated that he has no issue in using the kitchen, where he could get a drink himself (example below). The choice of drink may represent an offer of autonomy, yet the interaction's taken-for-granted nature – Ben arrives, sits down and waits for it to happen - highlights how in such circumstances he knows himself as a supported person.

He lifts his head up, takes his apple and crisp packet and walks over to the bin with a red but calms face. He returns and gathers his jigsaws from his locker as he did the previous week (lifeworld notes, 8th April).

Part of Ben's position as an inhabitant of the Hall means that support workers come and go. He is the permanent element in the dyad, meeting and spending time with one or two support workers across each day. Ingrained interactions such as the offering of drinks provide an opportunity for support workers to establish their place within the dyad by demonstrating that they know their roles. This creates a shared sense of comfort as their expectation of one another is realised – in essence, it establishes a relationship with predefined rules that are drawn from Ben's past social experiences. Ben finds that new support workers are like previous ones. In a way, he already knows them. The supported aspect of Ben's identity is confirmed and the uncertainty that exists when two people meet each other - seemingly exacerbated in meetings between inhabitants and support workers (detailed below) – is reduced.

...the person that was supposed to support Ben in the morning had just recently started and had not worked with him before. As such, she was anxious about meeting him for the first time and being observed and so did not want me to observe (ethno notes, 9th April).

Although there are particular interactions that are expected to take place as part of the dyadic relationship, the transient nature of support workers means that they can be unsure of the particulars of Ben's day-to-day routines and so rely on a general sense of a support worker/service user dynamic. In these circumstances, Ben responds accordingly to help the dyad complete the desired task. To illustrate, on weekly trips to the gym Ben and his support worker arrive at reception where he is asked by the support worker for some money to pay. He takes this out of his wallet and hands it to the support worker who hands it to the receptionist but they also require a gym card – 'he has his card?' (lifeworld notes, 15th April). Here the response from the support worker varies, some look to Ben (lifeworld notes, 15th April, 10th June) while another looks through the cards in Ben's wallet (lifeworld notes, 8th April). Ben knows that the receptionist requires his card – he recognises in the latter example that his support worker has picked the wrong card and so moves his hands away and corrects him – yet on all occasions he waits for an action from them before handing it over. Once again one sees how an everyday interaction entrenches Ben's experience as the supported. Despite Ben's greater understanding of the situation, his support worker is the one to speak to the receptionist while he waits for their prompts. However, on noticing his support workers' struggles, Ben's position with the dyad shifts and he becomes the supporter, taking the lead on the situation and providing his card to the receptionist.

6.3 The Supporter

Ben as the supporter is a subtle but ever present part of his day-to-day experience, enacted through frequent observation of situations and interactions with a readiness to intervene when necessary. He may sit back and accept a supported position within the dyadic relationships – maintaining its consistency through particular interactions – but he rarely hands over full responsibility. The concern he has for the actions of support workers is evident as he waits to the side of them while queueing for cinema tickets:

Emma gestures to a till and they walk over, Ben takes out his wallet and takes money out his wallet and gives it to Emma. They wait in the queue for a moment, Ben keeps wallet held open, looking at Emma and waiting for the change. She pays while Ben looks over her shoulder, looking at both Emma and the till person alternatively. Emma gets the change from the till person and gives it to Ben who puts it in his wallet and puts that away in his bag (lifeworld notes, 10th April).

If a support worker appears as though they are making a misstep – something unexpected in how Ben sees the future unfolding – he provides some guiding direction to help them proceed appropriately. In

one example (lifeworld notes, 9th April), he uses a hand over hand technique to show his support worker where to apply glue during art – a technique often used by support workers to help teach skills; in another (lifeworld notes, 8th April), he verbalises to his support worker that they are attempting the wrong puzzle and points them to the correct one. Providing support to support workers is a necessary part of Ben's life at the day service as he is committed to a particular schedule and mode of activity that they not always aware of. While Ben allows them to fulfill their supporter roles in the dyadic relationship, he has no hesitation in reversing this dynamic when their actions demonstrate a lack of understanding of his plans – as one support worker says when Ben ignores his direction during a puzzle, 'I suppose you know this better than me' (lifeworld notes, 9th April).

Quite distinctively, Ben wears particular clothes on particular days and in doing so embodies the temporal structure of the week so that others can follow. A support worker and Ben's mother illustrate this in a discussion on his choice of clothes when returning from holiday:

Support worker – then on the Monday when we were coming home we took his Monday tee shirt with us cos we thought he might not want to leave if he didn't have it. But he didn't put it on, he put one of the new tee shirts on but then half an hour before we were picked up (to go to the day service) he run upstairs to change in to one of the Monday ones.

Mother – 'I'm not on holiday anymore' (annual meeting minutes).

Although Ben may experience a secure sense of self through his choice of clothes – confirming to himself who he is and what he will be doing on that particular day – this is subsequently shared with the people he spends time with – namely support workers – as they both live through an expectation of one another. The supportive aspect of Ben's identity helps himself and his support workers to maintain an understanding of their respective roles in the dyadic relationship, subsequently providing a stable manner of being with each other despite the transient nature of the people that fulfill the support worker position.

Where possible, Ben minimises the potential that support workers will act in ways that challenge his day-to-day pursuits by taking the lead and allowing them to follow. This is a recognition of his connection to the dyadic relationship in that he demonstrates patience and consideration towards support workers as people who are an intrinsic part of the activities he cares for. In the following example, Ben waits for a support worker (Emma) in the foyer of the cinema before they go for lunch:

The film has finished and Ben quickly gets up with his bag and heads out straight towards the loo. A minute or two later he

appears again, waiting outside the ladies but facing towards the exit. He edges forward, looking at the exit door and then at the women's toilets and then at the exit, waiting for Emma to come out. She does and he begins walking, out the exit across the car park to a restaurant he goes to every week, leading the way (lifeworld notes, 10th April).

Here, the experience is embedded in the dyad. Emma's presence is significant in his willingness to proceed as he makes sure she is in tow before moving on. Ben leads to help support workers to understand what they will be doing together without them needing to ask - he confirms his future dyadic experience through his actions such as when he turns on plug switches during art to communicate that after he will use the laptop (lifeworld notes, 8th April). The subsequent effect of this is that Ben's social experiences rarely involve directive engagement or communication – as many support workers commented, Ben prefers 'minimal interaction' (ethno notes, 3rd April). He lives in such a way so as to rid his days of the experience of acute confrontation that was observed when a support worker – deviating from Ben's usual schedule - attempted to verbally explain that they were going to write in his communication book (lifeworld notes, 15th April). Being a supporter is therefore intrinsic to Ben in creating a comfortable existence within his dyadic relationships as it instills methods for support workers to engage with him that are civil and courteous in the context of his experience of communication and sociality.

6.4 The Independent

Ben has an intricate understanding of his day-to-day schedule, demonstrated through the assertive way he organises and dictates activities (example below) within the busy and hectic context of the day service. He finds himself supported and supporting, yet at times Ben does not find a need in the dyadic relationship and instead solely pursues his interests whether or not support workers follow. This is Ben as the independent, focused on the task at hand with little mind for the activity that surrounds him.

He lifts his head up, takes his apple and crisp packet and walks over to the bin with a red but calm face. He returns and gathers his jigsaws from his locker as he did the previous week. There is now one support staff at his table (not engaging with him) and he begins quickly but methodically completing the jigsaws. Ian, his support worker from the morning, has begun started supporting another person at the other end of the room. Ben's support staff for the afternoon are upstairs with another

*person, the manager tells me that she'll be down soon
(lifeworld notes, 8th April).*

In the above example, Ben shows no hesitation in finishing his lunch and beginning his afternoon activity. His self-assured character means that support workers and the manager have no issue in leaving him alone or trusting him with access to the regularly locked kitchen, though they did show concern with how that may appear to me when they informed me of the incoming support worker. In this way, Ben represents a juxtaposition for support workers as they are aware of his autonomous capabilities within the context of his daily schedule yet are bound by their roles to act towards him in a supportive manner. When Ben initially meets support workers, his independence can present a conundrum as they seek to establish their position within the dyadic relationship through encouraging but ignored remarks (ethno notes, 1st April); over the course of time however, Ben quells their need to support by showing his competence and himself offering encouraging, gentle high fives to signify that it is going OK. Ben knows of himself as an independent person – he experiences this on a daily basis through the explicit way he commands his life – and so he has come to experience support workers as people who occasionally require a demonstration of this part of his identity. A discussion about an occasion in a charity shop highlighted this realisation for one support worker:

*Support worker – ‘...on holiday we were discussing a pingu dvd
and it was, we didn't expect him to do what he did, he took the
pingu dvd out from the shelf and just looked at us like 'I do
know what you're on about'' (annual meeting minutes).*

For some support workers, Ben's independent character creates a barrier to them engaging with him and so they give him space and allow him to proceed. The fieldmap below (Figure 9) illustrates this, as Ben enters the Hall from upstairs and begins completing puzzles, his support worker sits away from him despite the available space at the table. In such cases, Ben's experience of independence is a solitary one, working through his endeavours with focus and occasionally looking up to observe the room. This is not to say that he does not feel a social connection in these instances for Ben enjoys the presence of others without any direct engagement.

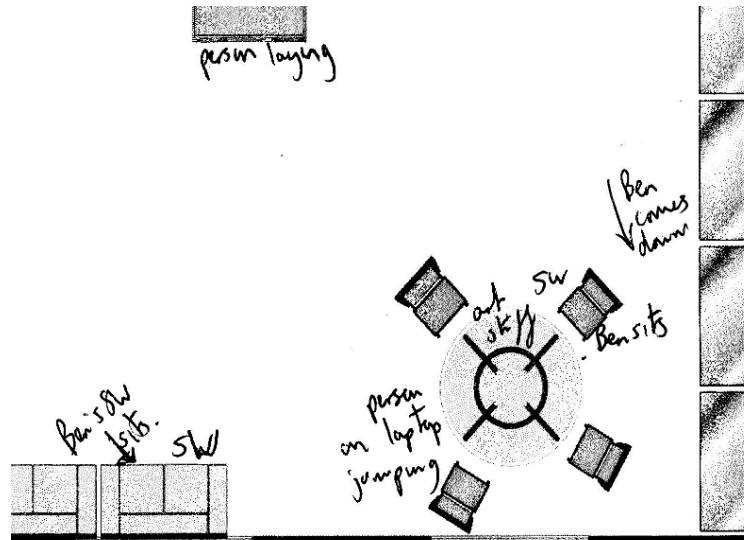


Figure 9: Fieldmap depicting Ben sitting separately from his support worker. On the right text reads 'Ben comes down. Ben sits'. On the left text reads 'Ben's SW sits' (fieldmap, 16th July, 12.10 p.m.).

Throughout environments and activities, Ben was observed taking a keen interest in the people around him with a clear attachment existing with particular individuals. One such person completes jigsaws in the Hall on Tuesday mornings where Ben – a fellow jigsaw enthusiast – sits and appreciates the skill on display:

He puts his fingers in his ears for 10 seconds then crosses his arms and begins to observe the man doing the jigsaw. He watches intently, occasionally putting his fingers in his ears but keeping his eyes on the jigsaw. He smiles for a few seconds and appears calm and contemplative. Ben bows his head into his lap. He makes an errrr sound and some da da das. He holds this position for about 30 seconds before lifting his head back up, his face reddened, and returns to observing the jigsaw work of his neighbour. This man is quickly assembling the jigsaw, turning over pieces and rearranging. Ben watches closely. This happens for about 20 minutes until the jigsaw is finished and the man puts it away... (lifeworld notes, 3rd April).

On each occasion that I observed this inhabitant completing jigsaws, Ben watched intently, communicating to no one though evidently absorbed. Ben's independent and unobtrusive nature provides ample opportunity to experience the company of others without direct interaction. These

moments - evident at the gym (lifeworld notes, 1st April), the cinema (lifeworld notes 17th April), a restaurant (lifeworld notes, 3rd April), a café (lifeworld notes, 10th June), the service sensory room (lifeworld notes, 16th April) and the Hall – involve Ben giving his close attention to the people that share his space. He is their audience. Over time, this instills in Ben a sense of community as the experience of people – their activity, characteristics and personalities – becomes rooted in his life and history.

6.5 The Partner

Support workers are not always a temporary entity for Ben. Some he has known and worked with for the eight years that he has attended the service. When there are periods in which Ben engages consistently with one support worker, when they become a permanent part in the dyadic relationship for a particular day of the week, it is evident that Ben forms an attachment that is distinctly present in his experiences. The unpredictable nature of the support worker diminishes as their actions and communication become entwined in a shared routine that brings them both a sense of ease. For a support worker to engage with Ben over time in a manner that he finds polite, that does not provoke uncertainty through misplaced actions, impacts him in such a way that they take a concrete position in how he envisages his future. They are part of who he is and what he will be on particular days – forbidden from working with him on other days as they do not belong there, as a support worker described to me:

Once, on a different day, the service asked Emma to support Ben, she went over to say hello but he turned away from her and gestured with his hands to go away. He then began looking down at his tee-shirt as if to say it's not the right day for us to spend time with each other – check my tee shirt! She says she's only ever supported him on Wednesdays (ethno notes, 3rd April).

When Ben experiences himself as a partner, the perilous demands of social interaction diminish and his comfort in the person's presence grows. This is enacted through small interactions that the two develop over time – markers that signify a commitment to repeating their day-to-day successes of the past and that take prominence in how Ben subsequently leads his life. A small but delicate moment happens each week at a bowling alley in which his support worker writes in his communication book as to how their day has been before reading it aloud to a captivated Ben:

Emma writes what they have done that day and Ben closely observes, arms crossed. After two lines, Emma says to Ben, 'have we had a good day?', and Ben nods. He then squeezes his

eyes closed for a moment, opens them and resumes watching Emma write. Emma picks up the book, points to the words and begins quietly reading them aloud to Ben. She finishes and Ben takes the book, puts it in his bag and starts walking towards the exit (lifeworld notes, 10th April).

This is safety for Ben. Trust in a person to live life as it should be – without surprise or contradiction. Failing to share it would bring into question what they had built together and who they might be in the future and, indeed, Ben is ready with the book on occasions when the support worker feels they are rushed for time (lifeworld notes, 10th June).

Partnerships are the opportunity for Ben to transcend his position as the audience of others – to change from the keen observer to the willing participant. As his assurance of his partner's actions is confirmed – given to him through the repeated living of their historical interactions – Ben offers some of himself. In a café after visiting the gym, Ben tells of interesting items in a newspaper, 'page by page scanning all the pictures and pointing out particular ones by tapping them and nodding, looking up at Ian (SW)' (lifeworld notes, 1st April); on another occasion, they share a thought on curries:

He (Ian) takes his phone out and reads through a recipe – cauliflower, potatoes, spices – as he does this, Ben looks over and observes the screen inquisitively. Ian says 'you'd enjoy this Ben, do you want to have a look?'. Ben nods and Ian scrolls through his phone to a picture, Ben taps the phone and Ian says 'I'll get you a better picture'. He puts the recipe into google and shows Ben a larger picture and says 'that looks tasty' and Ben nods and turns his head away (lifeworld notes, 8th April).

Here, the aforementioned supporter and supported aspects of Ben's identity — those that are thrust upon him through the dyadic relationships that he finds himself in each day – briefly disappear. He does not experience an urgency to ensure that they act correctly for their accordance has been proven. The vulnerability that sociality brings can be forgotten and for a passing moment, Ben lives outside the prescribed nature of the dyad.

From the outside, one may consider Ben's experiences as lacking sociality – he regularly sits and works alone, he ignores support workers, he leads activities, he consistently uses the same interactions – yet Ben is absorbed by the people that surround him. He lives through the frequent potential for confrontation that exists in the future actions of support workers and fellow inhabitants, though he is at the same time drawn to them through a fascination with their lives and daily routines. Ben draws from

the sociality of his past to recognise and assume ways of being with others that he knows of as polite and content. In doing so, the described aspects of his identity are embedded in the experiences of the community of people with which he shares his daily life.

6.6 A visceral world

The following theme discusses Ben's embodied experiences across the contexts and circumstances of everyday life at the service. This is both an exhilarating and vulnerable part of Ben's lifeworld due to the intense feelings and sensations that arise from his senses.

6.7 Feeling the environment

...Ben puts his head down to his knees for 30 seconds, shakes slightly and you can see his body tense. He then sits up and looks very calm, unfazed and carries on (lifeworld notes, 8th April).

Ben bows his head into his lap. He makes an errrr sound and some da da das. He holds this position for about 30 seconds before lifting his head back up, his faced reddened, and returns to observing the jigsaw work of his neighbour (lifeworld notes, 3rd April).

Ben's senses draw his environment in through a fluctuating process that peaks to discard all possible experience except that which is inside. Here at the apex, Ben halts the world outside as his eyes clench shut, his fingers press down into his ears, his head presses into his lap, his body tenses and he is enveloped by his voice. It is felt and held for a moment, 20 or 30 seconds, and then let go as if reset. The body is now free to proceed. Ben's daily experiences have an aspect of embodied feeling that is felt across his lifeworld. Brought to him through thought, sound and vision but felt viscerally within his body, at times it can bring Ben to a halt though he frequently quells this, responding to the fluctuations as they materialise through physical and vocal expressions. As a support worker said to me as Ben hummed with his fingers in his ears, 'he is feeling the noise' (ethno notes, 15th April).

During the film, about 30 minutes in, Ben has his eyes closed and his hands in a praying position just below his chin. He holds this for two or three minutes, opens his eyes for 10 seconds then closes again. He gently deee deee deees. A moment later, he puts his head towards his knees and holds it for 30 seconds. Lifts his head up, and flicks his fingers below his chin (lifeworld notes, 10th April).

Here at the cinema, Ben is the manager of his bodily experience, filtering the resources of his environment while peppering it with his own, personal inputs. The context is known as he visits once a week, to be surrounded by darkness but faced with the giant image and consuming noise. This is the exhilaration of a body in which sound and sight is tangible. The experience of a film has unpredictable intensities that he wrestles with in the search for joy, excitement or some other fulfilment - as a support worker commented 'the more vocal he gets, and when I'm watching him and he's smiling, it's all positive, he's expressing that he likes it' (annual meeting notes). It is an opportunity for Ben to take advantage of the performance of his senses in a place in which there are no unexpected distractions or stoppages and for this reason he usually sits alone (detailed below), leaving a space between him and his support worker so as to ensure he and his body have full autonomy. Though Ben is willing to cede part of this when faced with a busy cinema (lifeworld notes, 10th April), obscuring others from his horizons allows the film experience to be at its most absolute. In this cultural practice, Ben's body is enabled through social isolation.

The tickets are handed over to Anna and she points at one and clearly says 'Screen 4'. He nods. In the cinema Ben is guided up the stairs and to the end of the row by Anna who leaves a seat free in between her and him – she says 'it looks like it won't get busy' and says that in the past he has moved one seat away and likes the space (lifeworld notes, 12th June).

The laptop represents a similar funnel of experience to that of the cinema though this is more intense - Ben is consumed. This happens at the end of each day at the day service. The preceding activities and actions build towards this moment as Ben anticipates it by turning plug switches on at the wall hours before the laptop is used (lifeworld note, 8th April). There are distinct requirements for this – the laptop, a mouse, headphones and access to Youtube. It positions Ben in full control. He is not required to filter the performance as given to him, as happens at the cinema: Ben is Maestro and audience. Skipping through videos to particular parts, Ben repeats small sections over and over to concentrate particular sensations, lifting or pressing the headphones and moving closer then further away from the screen:

He pushes the headphones into his ears to increase the intensity of the volume before slowly removing them from his head to a distance of an inch. He smiles and eeeees. This continues – Ben searches through videos, selecting particular parts then plays for a moment. When he plays, he flicks his fingers, licks his lips, changes the volume intensity by

manipulating the headphones, closes his eyes and nods his head down. He'll do this for about 20 seconds before moving on to another section of a video (lifeworld notes, 2nd April).

These are videos that Ben knows and has watched through his life: perceptual talismans of his past that reinvigorate previous bodily experiences. At times, support workers gather around Ben to see what could be so exhilarating – some concerned, others entertained (lifeworld notes, 1st April) - but this is for Ben and they do not occur on his horizons. Perhaps in no other circumstance does Ben have such opportunity to experience himself as he wishes to. It has endless potential. Outside of this Ben must face the vulnerability of his senses in an unruly environment while here, as shown below, he has power and command.

During 'postman pat fun song factory' Ben has a period of intense eeeees, twinkle twinkle little star is sung and for a moment Ben flicks his hands the most intensely he has all afternoon. He then cuts this short but returns to it a few minutes later. His concentration is complete (lifeworld notes, 1st April).

The control that Ben exerts over his embodied experiences through the laptop is repeated when he listens to music each week in the sensory room of the day service. This is more serene though as Ben creates a particular, low lit environment in which to submerge himself, sitting with his ears just in front of the speakers with full control over the CD player – skipping, rewinding and restarting to listen to parts of a few distinct songs. Each week, Ben 'half pulls his sock off, twists it round and round then pulls it between his big toe and index toe, pulling it, holding for a moment then releasing' (lifeworld notes, 16th April). In these moments, auditory, visual and physical input is defined in the manner that has gone before so as to welcome that familiar bodily experience. Unlike that of the laptop, this is shared with support workers and other people that enter the room as Ben observes their participation. He cares for their experience by checking to see whether volume increases are appropriate (lifeworld notes, 2nd April) and turning his body towards his support worker to indicate that he is ready to leave once they are also finished listening – 'after about 50 minutes of the NOW CD, Ben turns 45 degrees towards Ian. He has done this in previous weeks and is perhaps anticipating the end of the music session...' (lifeworld notes, 11th June). The embodied mode with which Ben experiences music thus extends out to the ways in which those around him also live through it (example below). He has an audience and in sensing that responsibility, creates and manages an environment in which he feels that both can have an amicable time.

Ben turns off the lights so it is dark with only fairy lights on the ceiling and a light tower that changes colour constantly. There is a large ball pool in one corner, a small sofa in the other (Lucy sits on this), next to this is a small coffee table with the CD player and Ben sits crossed legged in front of this... He flicks through to Maroon 5... He stares up to the light tower while readjusting his socks (he took his shoes off when he sat down). For a slight second he flicks his hands around his ears, smiles slightly at me then looks back to the CD player, resets the song and bows his head once more, the CD player speakers are 20cm from his ears. He turns his head up to me, smiles, changes the song to Girls Aloud then McFly and bows his head again (lifeworld notes, 16th April).

6.8 Guarding the body in a social culture

In contrast to the orchestrated experience that Ben lives when listening to music or on a laptop, time spent in the Hall constitutes a myriad of sights and sounds. It is not the case that Ben necessarily experiences a busy environment more intensely – indeed, Ben showed no reaction to some of the loudest and most frantic occasions I observed in the Hall (ethno notes, 8th April) or when walking through a hectic bowling alley (lifeworld notes, 3rd April) – but that his embodied experience of the Hall requires and benefits from ongoing perceptual management. Manipulation of his ears, hums, vocalisations and closing his eyes balances out the incoming shifts in sensory landscape and gives Ben some autonomy over his inner body within social spaces. For Ben then, social life is embedded in a fluctuating embodied experience. He *feels* the surrounding community. Ben comes to know the life around him – the people, their activity and their habits – in relation to his bodily perspective:

He puts his fingers in his ears and vocalises da da das. It is quite loud and bustling around him, lots of different noises and different people talking. He stretches, yawns, vocalises a yeeeeeees and looks calm. It's as though he has to adjust his sensory perceptions until they are at ease with the current surroundings (lifeworld, 8th April).

Observations at the cinema and at the laptop show Ben's embodied experiences to be exciting and captivating, yet the significant intensity in which it can confront and be felt by Ben means that the unpredictable perceptual potential of people instills a level of apprehension into the culture of sociality.

Compounding this is the startling way in which direct, verbal communication engrosses Ben's attention and can build to a catastrophic embodied effect. In these moments, outlined in the below extract, the sounds of words and the advancing presence of another demands something of Ben, pervading his mind and body consciousness to the point of inundation. The feeling cannot be escaped and it must stop.

As he completes the counting activity Jeni asks him vocally if he'd like a drink, Ben 'hmmmmms' in a high pitched sound (what I understand to be no or a negative vocal) and turns away from her. She goes into the kitchen and brings out 2 bottles and shows Ben, he reacts the same way. She puts the drinks back into the kitchen and as she comes out she says 'so you don't want a drink'. Jeni sits back down next to him and says 'sorry Ben I was just trying to write in your book'. Ben vocalises the same high pitched 'hmmmmmm'. She says sorry again and Ben, clearly frustrated by his facial expression, quickly grabs her glasses off her face and drops them on the other side of the table... There is a sense of worry that spreads across the room. Jeni backs away from her chair. Emma comes out and gestures with her hands, pointing at Ben's activity on the table (lifeworld notes, 15th April).

When a person begins talking to Ben, a response is given quickly to quell the ensuing feeling before it reaches danger point. Ben makes frequent use of head nods to quickly acknowledge support worker statements or when he senses high levels of risk – as seen in the example above – vocalises a high pitch sound in an attempt to provide a negative response to the support worker and end the interaction. During times when Ben anticipates that support workers may communicate to him, before an activity is to begin for example, he guards his body by observing them closely: 'He turns round to face me – probably looking for the signal to go back down stairs – it is 5 minutes until the end of the session and Ben is constantly looking at me' (support worker observations). At other times, he is known to place his hand over people's mouths in a request for silence (annual meeting minutes).

Ben and his support workers conform to an etiquette in which direct vocal communication is considered tactless – 'he doesn't like too much chit chatter' said one support worker (ethno notes, 1st April). Through embodied communication – nods, high fives and facial expressions – Ben is able to experience relationships with support workers in a way that doesn't make him feel threatened. Ben enjoys their presence through a proximity in which he observes and listens, often giving them his close attention

so as to gently absorb their characters and peculiarities and the situations they share together.

Ben and Katie are both walking on treadmills – next to each other. They walk slowly. I am sitting on a machine behind and Ben watches me in the mirror in front of him. He runs his hands across the bars in front of him horizontally. He and Katie are in silence, walking almost in synchrony (lifeworld notes, 15th April).

The body's vulnerability dissipates as he relaxes and becomes confident in the other's decorum, so much so that at times he will invite them to talk out loud, such as when he creates a discussion about interesting pictures in a newspaper (lifeworld notes, 8th April) or the readings of his communication book that captivates him at the bowling alley each week. These occasions do not require anything of Ben and he enjoys their words without feeling that he must respond. This is the crux of social culture for Ben in that he and his body are most content when nothing is asked of him – when things, situations and people just *are*, seemingly unfolding around him so that his body belongs in the community and environment that he finds himself in.

6.9 Living the future through the past

The following theme outlines the salient nature of Ben's temporal and spatial experiences. Ben's day-to-day activities and pursuits follow a very specific order, relating to particular spaces in which particular things happen. This is a schedule that Ben has followed for many years since first coming to the day service. This means not only going to a gym on a Monday morning each week, but also using the same specific machines in the same particular order. Support workers slot into this schedule, adhering to it and generally acting in the ways expected of the particular circumstances.

6.10 Preparation

15 minutes into the walk and Ben turns around to look at the bike that Dan (SW) sits at – the one in which he intends to use next. Shortly after the treadmill begins to slow and then Ben presses stop and quickly jogs over to the bike, starting a 1 hour ride.

The future for Ben is an imminent concern filled with unknown potential. It is at his door waiting to come in and so he receives it by drawing from the certainty of his past. This is Ben distinctly rooted in space and time – experiencing his future through journeys previously travelled, following paths on which twists and turns are known and anticipated. The space he visits, the activity that happens and the order that this

occurs is a salient part of everyday life at the service, shown in the above example as Ben checks whether the correct exercise bike is available while on the treadmill. Each day – Monday, Tuesday and Wednesday – has a particular course that defines Ben's actions. The people around him follow this schedule with Ben acutely aware as to whether they adhere to it or require some direction. This is not the temporal structure of the service but that which Ben and his support workers have come to know as his own. This sense of ownership connects equally to the space in which Ben rests, utilises and moves through for in these moments, he inhabits it through a connection that he has nourished over numerous years.

Jeni sits back down next to him and says 'sorry Ben I was just trying to write in your book'. Ben vocalises the same high pitched 'hmmmmmm'. She says sorry again and Ben, clearly frustrated by his facial expression, quickly grabs her glasses off her face and drops them on the other side of the table... (lifeworld notes, 15th April).

On the infrequent occasions in which Ben faces a future different to the one that he anticipated, his body language, vocalisations and physical appearance (a red face) show a worry that preoccupies him, and so he seeks to correct it before he strays too far off route. As in the above example, his negative vocal directions failed to stop a support worker from diverting from the schedule as they attempted to write in his communication book and provide him a drink at an unexpected time; consequently, unease at what this may mean flooded Ben's consciousness – exacerbated by the support worker's verbal communication - and he sought to stop the incursion of his future by seizing the support worker's glasses and throwing them across the table (lifeworld notes, 15th April). From here, as other support workers scrambled to diffuse the situation, Ben was able to return to where he had left off and continue his art. Embedded into his history however, was the frightened experience of what happens when his schedule is not adhered to – the unnerving potential contained in the actions and communications of others that when realised is felt viscerally by Ben. Thus the experience of change further embeds a need to secure the future as experienced in the past: it is what keeps Ben safe.

There is a slight concern as the charger from his laptop is missing. The manager and Anna search through a number of lockers and locate it after about 2 minutes. Ben waits patiently. The manager says that she will send out emails to make people aware that they should not touch his charger. The laptop takes a while to load up as its updating. Ben watches it intently. Anna

says that she hopes it will hurry up, seemingly worried that Ben may get frustrated waiting (lifeworld notes, 17th April).

At times when the fulfillment of Ben's schedule is in doubt, as in the example above, the anxiety that has been felt in Ben's past experiences extends out to those around him even if he does not sense it. The significance of space and time to Ben captures the attention of support workers and he finds them endeavoring to fulfill his vision of the future. They are collaborators whose positions in Ben's past necessitates that they live as he does – responding to the structure that has been laid down through their actions and interactions and even feeling the dread associated with the possibility of change. They are part of his past and therefore part of his future. Ben helps to establish them in this sense of order by providing indicators of its progress such as communicating through nods and high fives that small moments have finished or leading them from one stage to another. Most vividly, Ben wears particular clothes on particular days in order to define who he and the support worker will be in relation to his previous experiences in those garments. Support workers are the most unpredictable entity that exists in Ben's day-to-day experiences and so he is drawn to preparing them for their shared future by asking them to re-enact the histories of their colleagues. They share and live a future that is familiar as it has been experienced before through those that Ben has previously encountered – as demonstrated every morning through the inevitable offer of drinks using two bottles of squash. The frequently changing support worker is therefore accustomed with a sense of permanence as Ben recalls that which has already been lived to see it lived again.

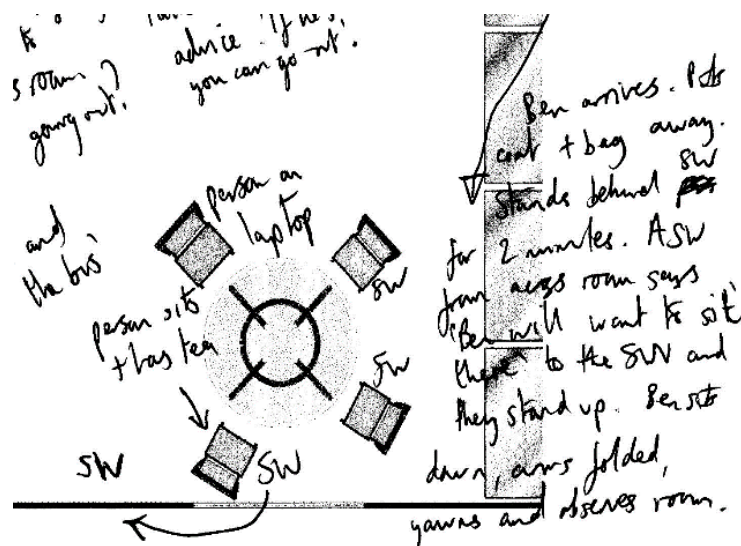


Figure 10: A fieldmap that illustrates a support worker instructing another to move out of Ben's space as he arrives.

Text reads: 'Ben arrives. Puts coat and bag away. Stands behind SW for 2 minutes. A SW from across room says 'Ben will want to sit there' to the SW and they stand up. Ben sits down, arms folded, yawns and observes room' (Fieldmap, 19th August, 9.50 a.m.).

The attachment that Ben has established with space calls on the people he encounters to abide as though Ben owned it. Ben exudes a confidence that has grown through being part of each individual space so that as he travels through his day, as in the above fieldmap example (Figure 10), people organise it to ensure that he rarely faces any barriers. Access is assured and this enables Ben to find the activities that he expects: for the order to continue as according to the past. Activity cannot happen anywhere or at any time for it is embedded in the time and space that has come before; therefore, a drink handed to Ben in the sensory room was taken to the Hall to consume before returning back to the sensory room (lifeworld notes, 21st May), and despite being a jigsaw enthusiast, he refuses the opportunity to enjoy one while waiting an hour before leaving for the cinema (lifeworld notes, 10th April). For Ben, this is what is correct and what feels *right*; not always just a sense of how he needs to be in the world, but also a physical reaction to the unfolding of previously lived experience as demonstrated when he feels the need to readjust his socks at the same point while at the gym each week (see example extract below). The past embodies Ben so as to reinforce his future perspective. He is physically assured of it.

Ben stops peddling and takes off a shoe. He very carefully brushes down the sock before returning the shoe. However he is not satisfied and takes off the shoe again, slightly readjusting the sock and again brushing the sock gently. He puts the shoe back on and returns to his gentle peddling (an example of Ben's weekly sock adjustment - lifeworld notes, 1st April)

Activity appropriates space so that when a physical space changes but the activity conforms to the expected schedule, such as when Ben goes to a different cinema to that of usual, it is not experienced as different to his past and is thus admissible in his future. The end of an activity is the signal to move to the next stage and Ben makes certain of this – waiting until the end of film credits at the cinema (shown below) and intently watching the gym machine shut down after getting off.

During the film, on a few occasions, Ben puts his head into his knees like he does at the day centre. When he lifts his head up, he puts his fingers in his ears and makes an errrrr sound... He sits till the very end of the film credits, sitting calmly and looking at me and Emma to check if we are moving. Once finished, he moves fast and heads straight to the

toilets (lifeworld notes, April 3rd).

In this way, the activity that fills Ben's days constitutes more than a group of hobbies or interests for they are a tool with which he situates himself in the temporal world that he knows and is connected to, that which he has experienced in his past. Each represents an assurance of the next and so to deny one would bring into question the others and therefore the future would be unknowable. The attention to detail that Ben dedicates to his activities means that he faces his future with credence in the way it will unfold and in doing so has the opportunity to focus on what is at hand as opposed to what is forthcoming.

6.11 *Belonging in time and space*

Ben looks over at me and I give him the thumbs up. He maintains eye contact for 20 seconds then looks back at the CD player and returns it to a Ronan Keating song he has been playing many times over. There is a low, soft chair next to him and he places his forehead on the edge so his eyes are directed at the floor. He keeps his head here for 2 minutes without moving and with his eyes closed. He looks very peaceful (lifeworld notes, 2nd April).

The experience of a certain future stabilises Ben in the present and at these points, as in the above example, he lives without regard to the schedule that bounds his day-to-day life. At these moments in time, Ben is completely comfortable with where he is situated and the concept of time drifts away. This occurs at the juncture at which – as if to obscure it - space meets time in the expected manner and Ben is able to live in the according way and participate in that moment's related activity. In saying activity, I refer to what Ben does here which could mean the aforementioned hobbies or occupations but also merely being in and experiencing the situation – its environment, people and goings-on. Until he is faced with the next step – perhaps a support worker indicates it is time to leave, or the time he sets on the gym machine runs down – Ben is at his most confident, relaxed and interested in the proceedings.

The Hall is now almost entirely empty apart from three support workers behind Ben. A member of staff comes out the kitchen and offers round a few French fancies... and offers the box to Ben who eagerly takes one and licks the icing off the top before devouring the lower block. He looks at me and looks away when I look back. He is calm and observing the room, vocalising some da da das (lifeworld notes, 3rd April).

In living such a distinct daily schedule, Ben's attachment to its related space – the comfort and security that it offers – extends out to the people he encounters. When other people are a part of Ben's experiences, they become rooted in the history that he draws from to live his future. He shares in their

activity as they share in his – watching a fellow jigsaw player enthusiastically each Wednesday morning (lifeworld notes, 3rd April), or creating art with a support worker each Tuesday afternoon (lifeworld notes, 9th April); and so over time, he begins to look to them to reinforce the sense of belonging that exists in the experience of an anticipated future. At times, particular persons will embed themselves in such a way that it is too difficult to experience them in ways other than that he knows them to be, such as a support worker that he cannot engage with on days other than Wednesday as they have been a consistent part of it in the past. People come to belong in Ben's schedule and as is the experience of activities and spaces being at their correct points, they too instill a sense of security that enables Ben to participate in their shared situations. Interactions that are not usual parts of the schedule, those that have not been scrutinised through previous experiences, are openly initiated or responded to by Ben, as in the example below in which a support worker, using direct verbal communication that is so often fraught, asks him for slightly better table manners. The person does not represent a risk to Ben's future as they have shown themselves as entwined in its temporal and spatial structure: they belong there as Ben does.

He takes the spoon and begins to eat this up, wiping the sides of the dish with his fingers and licking the sauce off them. He does this until it's almost completely clean and then picks the dish up and licks it. 'Ben!' says Anna 'maybe trying using your spoon'. He puts the dish back down and continues using his fingers to mop up the food. Anna says 'that's fine but you can't lick it!' (lifeworld notes, 17th April).

The past is Ben's sanctuary at the day service. Its safety is proven certain by living through it each week. The environments, people and activity that Ben experiences are the talismans of his past, acting to ground him in a world that he knows. His very future depends on them. Rooted to these spatial and temporal structures, this is where Ben feels sincere belonging. Sincere in that he does not take it for granted – only once each stage has been met does he accept that the space is there for him and that he can live in it as he wishes to, with concern for the people and activity in which he is surrounded.

Chapter Five – Findings

Part Two – Everyday Life at the Day Service

The second part of the findings chapter addresses the first aim of the thesis more broadly: to explicate everyday life within day services from the perspectives of autistic people with profound learning disabilities. As detailed in part one, this perspective was drawn from understandings gained during fieldwork through using lifeworld fractions (Ashworth, 2016) to think phenomenologically while doing phenomenology (Berndtsson et al., 2007): the methodology developed and described in Chapter Three. The data drawn from to detail and illustrate the analysis is primarily fieldmaps, as used in the third fieldwork stage (Chapter 4.20), though evidence is also presented through fieldnotes collected in stage one and two.

The analysis identified four themes that can be said to characterise everyday life within day services: first, ‘Spatial customs’ details the spatial rules of the Hall and the way this holds accepted ways of acting across day-to-day life. Then ‘The routine of daily life’ offers understandings of the temporal aspects of movement and activity in the Hall that allow a ‘business as usual’ atmosphere in a busy and hectic space. In ‘A sense of risk’ the activity and habits of support workers is shown to embed risk into daily life, with the accepted customs of the Hall providing an antidote to such perceptions. Finally, ‘A place to learn; a place to teach’ explores the ways in which teaching and learning are key parts in the running of daily life, detailing a storytelling teaching method that maintains the history and community of the Hall.

6.12 Spatial customs

This theme refers to the ways in which the physical space at the service is used by its people and how this relates to ways of acting and behaving in day-to-day life. There are two subthemes: ‘space management’ looks at the ways in which people organise space and how this creates unwritten spatial rules, while ‘ways of inhabiting space’ finds ways in which people live within these spatial structures.

6.13 Space Management

How space is managed can be seen by looking at two areas of space – first, the central area as it connects primarily to its inhabitants and secondly, the kitchen, small office and manager’s office as it connects to the support workers. Within the central area the inhabitants have or develop personal areas of space that come to be known as theirs:

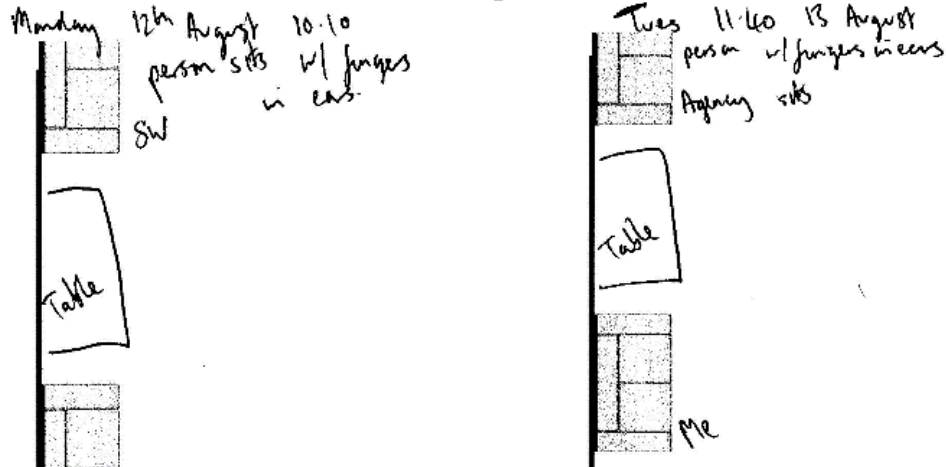
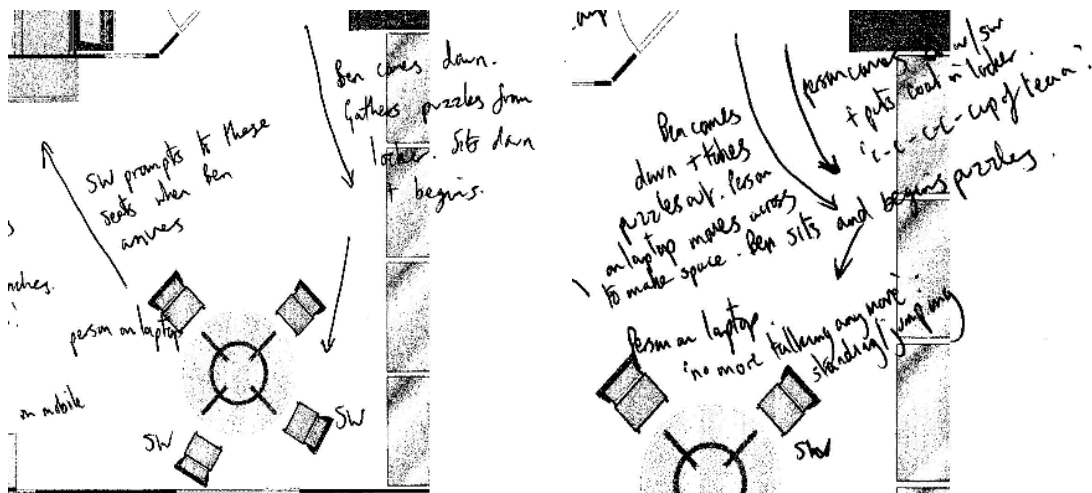


Figure 11: A fieldmap showing a person who consistently sits in the far corner of the Hall. Text reads: 'person sits w/fingers in ears'. (Fieldmaps, 12th & 13th August).

These established personal spaces are managed by both inhabitants and support workers though they only relate to attachments with particular inhabitants. Most inhabitants that spend the majority of their day at the service (as opposed to persons that arrive in the morning and then go out for the day) occupy distinct areas of space across the day and this might constitute a particular area of seating – as seen in the above fieldmap extracts (Figure 11) – an area in which to move within, a table to sit at, a darkened room or a tent. These areas are understood to be occupied in line with their connected inhabitant's day-to-day schedules; so, while space is used freely as people come and go, people are aware of and respond to the incoming arrival of particular inhabitants such as the occasions in which support workers prompt a person to move table prior to, or as, Ben arrives:



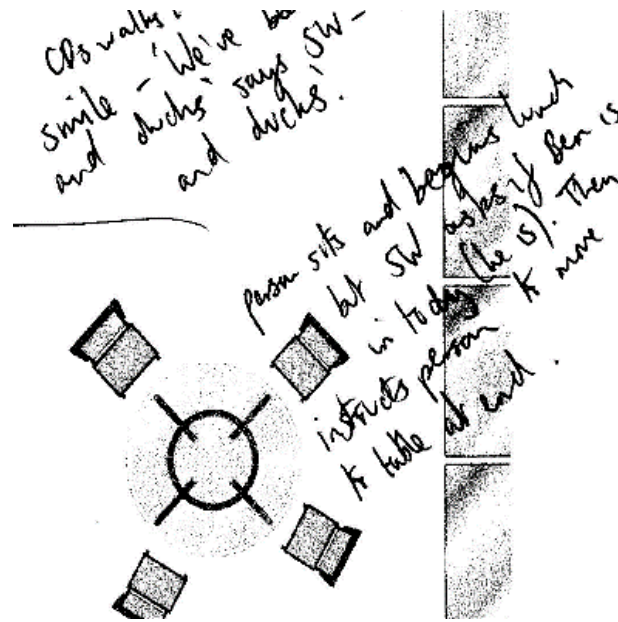


Figure 12: Three fieldmap sections depicting support workers freeing up Ben's area. Text reads:

'person on laptop' 'SW prompts to these seats when Ben arrives' (fieldmap, 13th August, 11.50 a.m.);

'Ben comes down and takes puzzles out. Person on laptop moves across to make space. Ben sits and begins puzzles.' (fieldmap, 30th July, 11.40 a.m.);

'person sits and begins lunch but SW asks if Ben is in today (he is). Then instructs person to move to table at end' (fieldmap, 20th August, 12 p.m.).

At times, those with established personal areas manage it of their own accord – communicating to others that they need to vacate the space or calling on support workers to arrange it for them. In one instance, a person loudly vocalise when another inhabitant attempts to lay down on an area of chairs they see as their own and this quickly draws the action of three support workers who prompt the person to lay in a different area (ethno notes, 11th June). Such a dramatic expression reinforces a sense of ownership and protection and also directs others – particularly support workers - as to how they should use the Hall during specific time periods. Elsewhere, this is communicated more subtly: Ben arrives and finds that the seat that he expects to sit in is taken by a support worker and so merely stands behind them silently until they are prompted by another support worker to move (shown below: Figure 13).

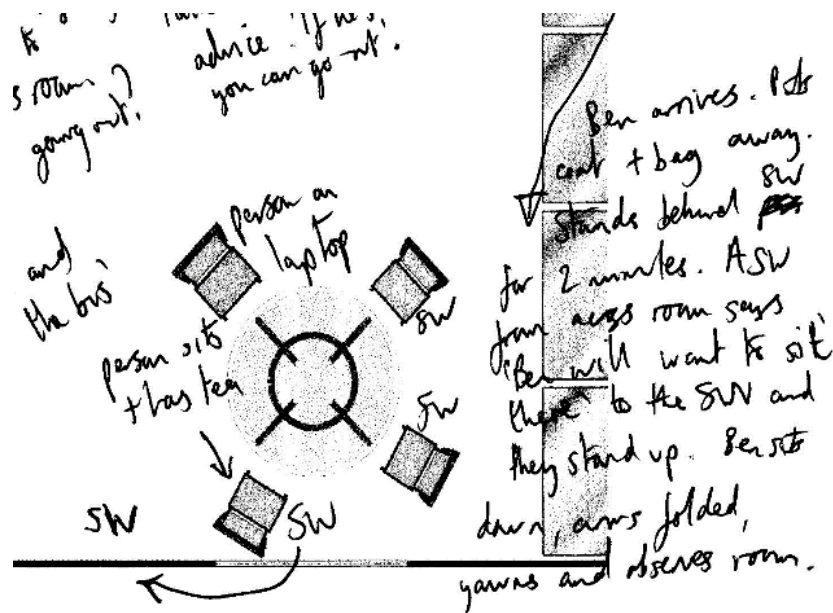


Figure 13: Fieldmap section. Text reads: 'Ben arrives. Puts coat and bag away. Stands behind SW for 2 minutes. A SW from across room says 'Ben will want to sit there' to the SW and they stand up. Ben sits down, arms folded, yawns and observes room' (fieldmap, 19th August, 9.50 a.m.).

Through personal spaces, inhabitants and support workers create rules relating to how space can be shared and managed within the Hall. For example, an inhabitant who does not like his peers to sit at or lay on his chairs does however share his space with support workers, conducting an interaction each morning in which he seeks assurance to sit down with them:

Alfred arrives and stands near the lockers and takes off his shoes before taking a support workers hand and leading them through to his seat where he initiates a process of seeking confirmation to sit down through small points, hisses and face gestures. The support worker guides him through, and they sit down after about 5 minutes (ethno notes, 8th April).

Another inhabitant occupies their own room at the far end of the Hall in which lights are kept off (ethno notes, 12th June) though people move freely in and out. Ben often shares his table space with others – seemingly unbothered unless they get too close (lifeworld notes, 9th April) – though support workers are seen to prompt his peers away from him if they feel they are encroaching (lifeworld notes, 17th April); thus, managing personal areas for some can lead to the blocking of space for others. For inhabitants with broad areas of personal space, walking back and forth and in and out the Hall, space becomes shared with

each other and requires a following support worker to ensure that they do not impinge on another's established area or movements (see below: Figure 14).

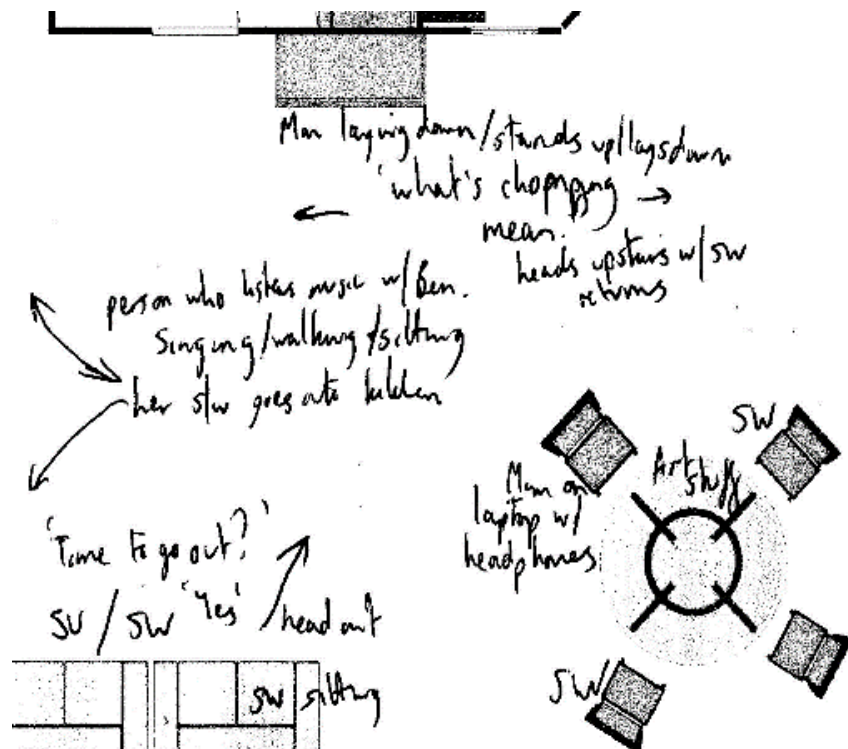


Figure 14: Section of fieldmap showing two persons who share in the same space while moving (arrows depict walking). Text reads:

'Man laying down/stands up/lays down. (Says) 'what's chopping'. Heads upstairs w/SW returns.'

'Person who listens to music w/Ben singing/walking/sitting. Her s/w goes into kitchen.' (fieldmap, 16 July, 11:40 a.m.).

The temporal character of personal spaces within the Hall – in that they are apparent in relation to the times that particular inhabitants are in or out – means that environmental features of the Hall are managed in similar accordance. While the main spatial environment of the Hall remains largely stable across temporal dimensions – one notes a single table disappearing during the fieldwork period of 5 months (this was prior to adopting the fieldmaps method in stage 3) – smaller features are seen to come and go in a regular manner. A laptop playing pop songs is set up on Tuesdays and can be heard throughout the day as part of the personal space of one inhabitant who, at times singing, walks in and out of the Hall, and whose temporary absence can cause confusion for those unsure who is listening to it (fieldmap, 20th

August, 11.50 a.m.). Even when it causes discomfort to support workers and the inhabitant is not in the room, their personal space demonstrates a self-sufficiency as it is not intruded and the laptop is left on (ethno notes, 9th April). Elsewhere, a tent resides in the corner of the Hall and has another laptop added to it on Monday mornings, playing Mr. Bean on Youtube and remaining absent until an inhabitant is directed to it by two support workers (fieldmap, 12th August, 9.50 a.m.). At times inhabitants themselves become spatial features, laying across chairs over the Tuesday lunch period (as seen in the below fieldmap, Figure 15), while the activities that some do can also become part of the furniture, such as the large bowling that takes place around the same Tuesday lunch time. These brief but temporally consistent spatial features help to manage the expectations of daily activity and its related persons, acting as signposts that organise the flow of people through the Hall.

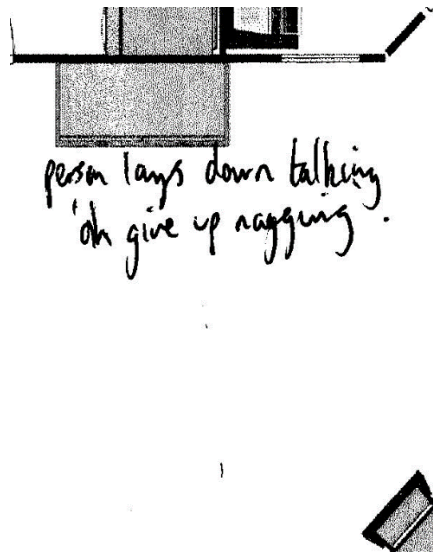


Figure 15: Section of fieldmap depicting inhabitant laying down talking aloud. Text reads:
 'person lays down talking 'oh give up nagging'' (fieldmaps, 16th July, 11:50 a.m.)

The lock on the door of the kitchen means that it is one of the few spaces that support workers manage access to, changing the rules dynamically in accordance with its internal and external conditions. Generally, early mornings see access granted to all comers as people flow in and out (primarily support workers), making drinks or breakfast, putting lunch into the fridge or socialising. However, the kitchen becomes increasingly regulated as more inhabitants arrive. So, for one inhabitant arriving early, making a coffee can be as simple as walking into the kitchen and exclaiming 'I want a coffee I do' (ethno notes, 10th April), whereas on another, later occasion, they are blocked from going in by a support worker who advises

person comes in w/ sw
+ puts coat in locker.
'c-c-c-c-up of team?'
person arrives puts
coat + bag in locker
go to the lounge.
cup of hot-cream

4-5 days

Person sits down - instructs SW
to put up away.
SW
'walk at
Roverdhan'
'no room here'

168

‘person comes in w/SW and puts coat in locker. “c-c-c-c-cup of tea”’ (fieldmaps, 30th July, 11.40 a.m.);

‘person arrives puts coat and bag in locker. “Go to the ‘looooo” – “Go on then” – “cup of teaaaaaa”’ (fieldmaps, 5th August, 9.00 a.m.);

‘person sits down “teaaaaa”. Instructs SW to put cup away’ (fieldmaps, 16th July, 12.00 p.m.)

Effectively, the management of the kitchen brings about wider spatial customs as inhabitants respond to its inconsistent accessibility by making use of it through negotiation or instruction, or through ingrained social interactions connected to their own personal areas (as seen in Ben and his support workers).

A service user, Chris, arrives and puts his bag away and walks up to one of the tables that has four support workers seated around it. He says nothing, just stands there for a moment. One of the seated support workers says to another, ah give him your chair, and another stands up and says ‘Chris would you like a drink’ at which point Chris says yes and takes the available seat. (ethno notes, 8th April).

Inhabitants have privilege over space – as seen earlier when Ben stands behind a support worker until they are instructed to move by another staff member and in an identical circumstance with another inhabitant (above) – with personal space being managed with highest priority and below this a more generalised sense in which inhabitants and support workers respond to the fluctuating capacity of the Hall. That is to say, not all inhabitants appear to connect to personalised areas and these people, along with support workers, move from table to table and seat to seat. While the managers’ office is for them a consistent space, support workers remain transient – they have primary use of a small office next to the kitchen however inhabitants are seen to use or occupy this at times, sometimes to the frustration of support workers (ethno notes, 8th April).

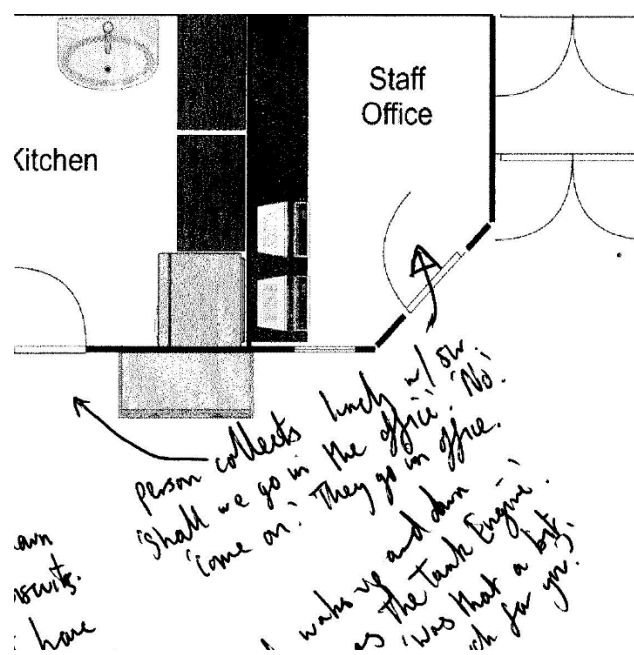


Figure 17: Fieldmap extract depicting a support worker managing space. Text reads:

'person collects lunch w/SW "shall we go in the office" (says SW), "No" (says inhabitant), "come on" replies SW). They go in the office'

This hierarchical nature thus locates the need for support worker space lowest, with inhabitant space of greater significance and personalised areas surpassing both. Support workers act to enforce this hierarchy, creating space by directing the Hall's people, such as the support worker directing an inhabitant into the staff office for lunch (fieldmap above, Figure 17), or prompting inhabitants out of the Hall when it is considered overcrowded (fieldmap, 30th July, 12.10 p.m.). Therefore, at times of crowding – as is the case during many lunch periods – the people of the Hall can be guided by a sense of spatial order connected to the hierarchy and its related persons.

On the fieldmap 16th July, 12.00 p.m., a support worker remarks 'no room here' – the Hall is full. Without space management then, the Hall may fail to provide adequate space for those that inhabit and pass through it. However, by creating and blocking space, establishing personal areas, relating space to the Hall's temporal structures and following a space hierarchy, people within the Hall are able to go about their day-to-day lives with a sense of order and expectation. Connected to this spatial order, and what I will explore in the following subtheme 'ways of inhabiting space', is the manner in which people live within it.

6.14 Ways of Inhabiting Space

The management of Hall space gives its people an expectation of their day-to-day boundaries and linked to this comes a sense of what a person does within this space. As detailed, some of the Hall's inhabitants create and maintain established personal areas that range from areas of chairs to wider spans of space that extend out of the Hall, while others – as well as support workers - are more transient and find space in line with the Hall's ongoing spatial fluctuations. This spatial expectation means that people can move freely into, out of and within their related areas – they do not need to worry about their being a lack of space to fulfil what they want to do or how they want to do it because it is there every day. We see this first during mornings when inhabitants begin to arrive at the service – often dropped off by buses or family members, they travel through the front door to their related space and begin:

A middle aged lady and her son (service user) walk into the main hall and he heads straight to the cupboard where he takes out a jigsaw then sits down. (ethno notes, April 10th).

Once established in a space, inhabitants are able to move freely. Clear examples of this (Figure 18) are two particular inhabitants who traverse the Hall on a regular basis, walking back and forth and in and out:

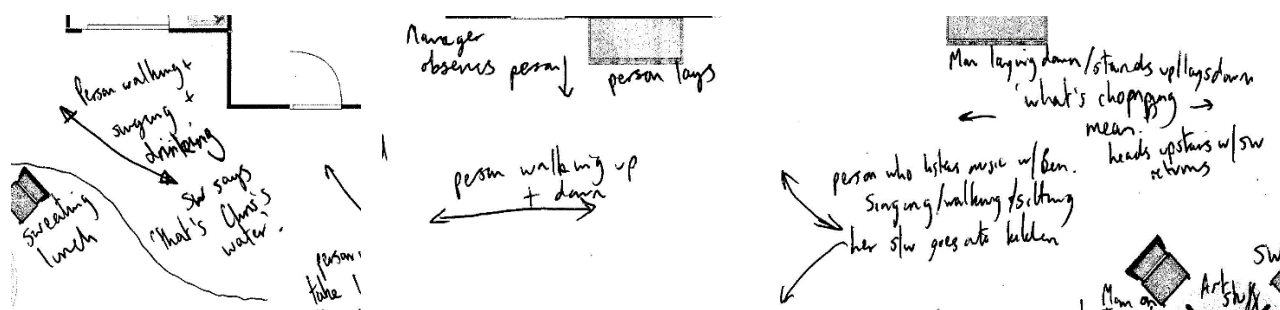


Figure 18: Fieldmaps depicting inhabitant movement with arrows (fieldmaps 16 July, 12:40 p.m.; 30 July, 12:40 p.m.; 16 July, 11:40 p.m.)

Their movement is an innate part of their day-to-day activity that fills the space that they inhabit. There are very few boundaries as it has become an accepted way of acting that is particular to their established space and their ways of living. However, when people enter the Hall that are unaware of these spatial customs – both the established space and how people act within it – problems can arise. In the example below, one of the inhabitants attempting to leave the Hall towards the car park – a place that they walk around on a regular basis – yet on this occasion they are supported by an agency support worker who is new to the Hall and unaware of its spatial customs:

I see through the door the lady who was singing rushing towards the front door and her support worker attempts to pull her back – asking her not to go outside (not sure why) – the support worker is only there for the day and has not met her before – I observed the manager giving her some brief instructions before they were introduced. (ethno notes, 28th May).

For this inhabitant, the expected freedom to travel in and out of the Hall is overridden by a new-comer. The earlier instruction by the manager demonstrates that – even with direction - these customs are not inherently obvious and that people must learn of them over time. This is further illustrated in an occasion with the other wandering inhabitant (example notes below) when at one end of the room the manager informs another agency support worker that the person enjoys going outside, while at the other an inhabitant asks the person if they would like to go outside to which he does. Here, the way the inhabitant acts within their established space is known by another inhabitant whereas the temporary agency support worker must be told.

The manager is in the corner talking to a support worker (agency), she says of the person the support worker is supporting that he shouldn't be pressured into doing anything and he likes going outside for space. This person walks up and down the room and the person sitting behind Ben (another service user) – who has overheard this conversation – says to the man 'are you going outside?', and he does (ethno notes, 9th April).

Freedom of movement expands the Hall's capacity – it allows for people to be part of its day-to-day activity without the need for greater space or further management. A number of inhabitants who do not occupy regular areas regularly pass through to greet and socialise with others – high fiving (ethno notes, 21st May) or asking people to repeat phrases (fieldmaps, 15th July, 10 a.m.). Support workers from other services come and go, picking up inhabitants and asking how their day has been (fieldmaps, 16th July, 12.40 a.m.); trades people and, on one occasion, paramedics pass through without hesitation (below); while parents often pop in to talk to service staff in the morning (fieldmaps, 15th July, 9.10 a.m.). The sense that the Hall is a place of which people can move freely in and out of means that support workers and inhabitants do not question or respond to the frequent flow of people – as seen in the lack

of response from support workers when paramedics came in – leaving them to proceed with their days as normal.

Two ambulance people arrive and walk through the main doors into the main hall, 'who are you here for?' asks a support worker, 'we don't know' replies the paramedic. Another support worker comes over and says 'he's upstairs' and they head up. The staff (around 8 or 9) and service users make almost no reaction to the sight of 2 paramedics (ethno notes, 10th June).

This sense of freedom can also be understood in relation to how the Hall's people express themselves within space. This refers to how particular forms of expression become known customs that are attached to particular individuals, pairings or groups – both support workers and inhabitants - and subsequently enacted within their related areas of the Hall without question by others. As one might expect, support workers use talk to express their thoughts on personal and professional matters and this happens throughout the day, whether they are supporting or not, and in line with their transient use of Hall space. That is, they abide by the spatial hierarchy to ensure space is available to inhabitants though as they are not themselves connected to space, the Hall's freedom of expression means that they talk anywhere with minimal filters - as we see when a support worker talks to me while supporting Ben during art (at a table in the Hall):

...she tells me about a place she worked at and the people that lived there (a residential support service). She says that she was very fond of one person in particular but that the person died unexpectedly and she left due to this. She goes on to talk about how a person she supports is very frightened of dogs and how he is the same age as her son and that they share a name – that this makes her reflect on the both of them (her son and the service user). She tells me about her family. Throughout she continues to tear paper and Ben, fully focused, glues and sticks these into large, colourful blocks. When Jill is too slow, he holds out his hand expectedly (lifeworld notes, 16th April).

A similar sense of expressive freedom is also observable in the inhabitants though their methods are more individualised and could include: singing, talking aloud though to no one in particular, jumping on the spot, asking persons to repeat phrases, flicking hands, physical gestures, hugging, clapping, skipping or vocalising (example fieldmap below, Figure 19). As these expressive acts are linked with the related areas

and schedules of particular inhabitants, they become part of the day-to-day environment; in other words, if the person jumping on the spot was absent on a Tuesday lunch, or the person walking and talking aloud could not be heard on a Monday morning, or indeed, if support workers were quiet throughout a day, it may seem more noticeable than when they are there.

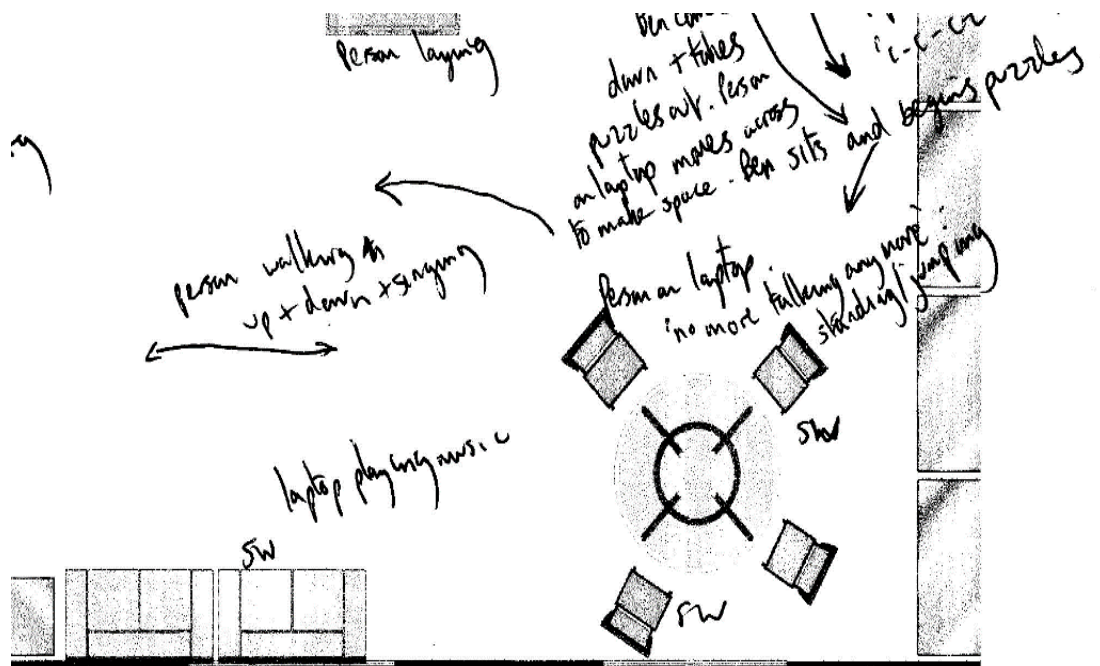


Figure 19: Fieldmap section showing person singing and another jumping on spot. Text reads:
 'person walking up and down and singing';
 'person on laptop – "no more talking anymore" - standing jumping' (fieldmaps, 30th July, 11.40 a.m.).

The sense of freedom of expression and movement – alongside the Hall's other spatial customs - means that support workers and inhabitants come to inhabit space in ways that they are comfortable with; that is, the shared understanding of how particular individuals act in specific areas means that events only requires attention if something unexpected happens, leaving people to proceed with their day-to-day projects. For this reason, we see people taking opportunities to rest despite the often busy Hall. In the example below (Figure 20), an inhabitant knocks a large amount of Lego onto the floor that makes a huge crashing sound, though a person laying inches away does not show any response:

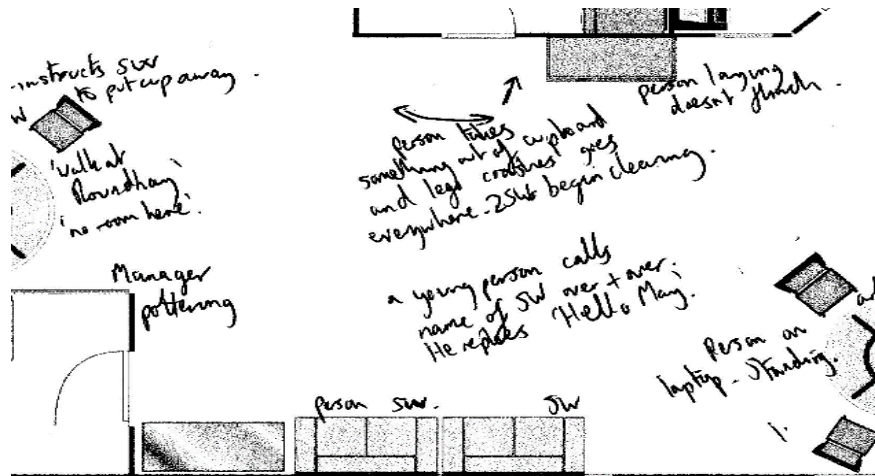


Figure 20: Fieldmap showing the lack of reaction from an inhabitant who lays next to a large crash. Text reads: 'person takes something out of cupboard and lego crashes and goes everywhere. 2 SWs begin cleaning' – 'person laying doesn't flinch' (fieldmaps, 16th July, 12.00 p.m.).

Others engage with the space in ways that are perhaps unique to their sensory perceptions, such as when Ben manipulates his auditory environment – 'he is feeling the noise' said one support worker (ethno notes, 15 April) – or when another inhabitant is given time to rest his head on some seating (ethno notes, 10th June).

Refreshments are linked with opportunities to rest and support workers ritualistically provide drinks to inhabitants to signal a moment to relax (lifeworld notes, 28th May) and, as we saw earlier, inhabitants have come to expect these and will wait from their personal areas for them to be delivered from the kitchen. Lunch is delivered in a similar manner with support workers attempting to ensure each person has food, drink and space – sometimes to their frustration when inhabitants do not follow this temporally related way to act:

It is lunch time back at the day service. Ben has arrived back. There are three support workers attempting to persuade a man to eat his lunch. The manager comes out and says to him 'you must eat your lunch come and sit down'. He follows and begins sitting down at the same table as Ben, though stands up and walks off with a sandwich. (ethno notes, 15th April).

Support workers also rest to some extent – taking time to eat breakfast in the mornings or to sit and look at their mobile phones. This is not to say that the spatial customs allow for laziness or inattentiveness towards the ongoing activity of the Hall – we often see support workers completing paper work and responding to events near the kitchen or as people arrive – but that the regularity of everyday life allows occasions to relax. Indeed, when there is commotion, such as when an inhabitant throws grapes out of the smaller office (extract below), support workers tend to give up opportunities to rest and instead gather to oversee the disturbance.

The support worker of the person in the smaller room is being told by another support worker about a previous person they supported who had to go into a mental health hospital as her behaviours at the service declined. She seems to be attempting to calm the support worker, who is frustrated by not being able to engage with the person in the smaller room, and to try and show her that it is nothing to worry about. A male support worker goes into the small room then comes out shortly after. He said that he had asked the person why she was being mean to her support worker, and she had said sorry (ethno notes, 8th April).

By looking at the ways in which space is managed and exploring the ways in which people live within space, the Hall has revealed itself to have inbuilt spatial customs that guide the day-to-day flow of people and events. Through this, the Hall's people are able to make use of its space even during times of overcrowding. Perhaps what is most crucial is the designation and connection of particular areas, as inhabitants and support workers are able to know and appropriately respond to the fluctuation of available space and, moreover, this allows the Hall's people to act and live with relative freedom and comfort.

6.15 The routine of daily life

This theme explores the overarching day-to-day routine of the Hall and its temporal character. It is important to recognise that the service provides a general temporal structure:

- The day begins around 9 a.m. when the majority of support workers arrive, gathering in groups to discuss personal and professional life, complete or look at paperwork, eat breakfast and drink beverages.

- Between 9 a.m. and 10 a.m., inhabitants arrive, put their bags/coats away, have refreshments (usually provided by support workers).
- 10 a.m. – 12.30 p.m. consists of two ‘sessions’ – periods in which inhabitants are scheduled to do particular activities with a support worker – often outside the Hall or leaving the service building.
- 12.30 p.m. – 1.30 p.m. – lunch period – support workers will often change who they are supporting during this time – perhaps some leave and others arrive.
- 1.30 p.m. – 3 p.m. – A third session.
- 3 p.m. – 4 p.m. – Inhabitants depart.
- 4.30 p.m. – Support workers depart.

Although this structure is not always adhered to by inhabitants as they pursue their own interests through individual schedules that support workers adapt to accordingly, it gives rise to broad reoccurring daily events connected to the gathering of people in space and time. During observations across the first two stages of fieldwork, this was specifically highlighted in and around morning (9 a.m. – 10 a.m.) and lunch (12.30 a.m. – 1.30 p.m. when temporal patterns are concentrated within the Hall. These can be represented through three primary routines: interactions, activities and movements. The first relates to routine interactions between people in the Hall, particularly inhabitants and support workers. Activities concerns what the Hall’s people *do* on a consistent basis, while movements pertains to the routine flow of people. It is important to emphasise their interconnected relationships – they anticipate and require each other and so disturbances in one area of routine would have implications for another. I will explore this in the following section, looking at how a sense of order is built as the different routines come together and repeat over time.

In the subtheme ‘ways of inhabiting space’, we saw that the Hall’s spatial customs involve a freedom of movement that is linked with personal areas and a spatial hierarchy; in short, there are limited movement restrictions as long as the Hall’s people use their allocated areas to move in and out of. Due to this, the Hall’s people are able to develop movement routines within their related areas that play out in line with their personal schedules. Observations show regular patterns of movement that are grounded in temporality - they include:

- Inhabitants arriving (individuals and groups).
- Inhabitants leaving.
- Particular inhabitants walking in to interact with people and then walking out.
- Inhabitants moving between areas to take part in or organise activities.

- Particular inhabitants going in and out of the kitchen.
- Particular inhabitants walking back and forth.
- Support workers following particular inhabitants.
- Support workers gathering and dispersing in mornings.
- Parents of inhabitants coming and going in the morning.
- Support workers moving in and out of kitchen.
- Gathering of support workers and inhabitants across lunch period.
- An interchange of support workers around lunch.

Referring to these movements as being grounded in temporality means that they happen on particular days during particular periods of time; that is to say, they do not necessarily happen at specific times but are apparent in line with a regular order of activity at the service. So for instance, on every morning of observations, Ben arrived into the Hall to the lockers and then to his table area, though on each occasion this happened at a different time.

As the above examples suggest, routine movement involves individuals, pairs and groups. For support workers, we see a tendency to move in pairs and groups – as when supporting inhabitants and gathering with colleagues. Alternatively, inhabitants have more individualised movement patterns though these become paired when they are accompanied or followed by support workers. Group gatherings of support workers and inhabitants tend to happen only at morning, lunch and late afternoon periods as they move between their daily activities (shown in fieldmaps below, Figure 21). Characterising these routines are consistent and recognisable inhabitants (the same inhabitants come and go in the same patterns) with more interchangeable support workers (support worker movement is predictable but who the support workers are is not).

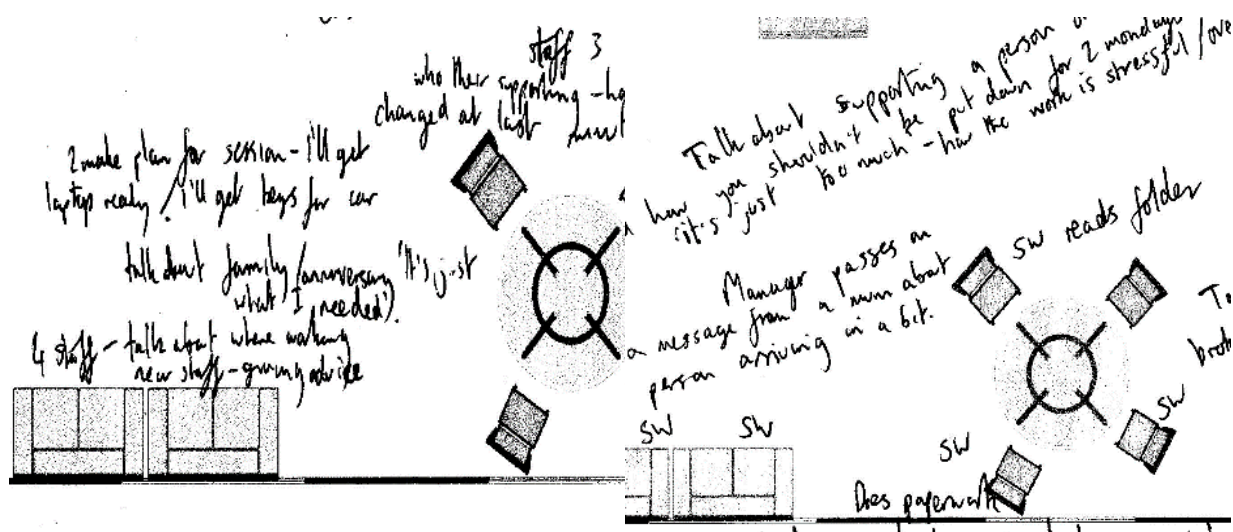


Figure 21: Two fieldmaps showing the gathering and chatter of support workers in mornings (fieldmaps 15th July, 8.50 a.m.; 12th August, 8.50 a.m.; 19th August, 8.50 a.m.).

For two inhabitants, routine movement is *part* of their routine activity in that walking back and forth through the Hall – incorporating singing and speech - is how they use the space at particular times; for other inhabitants though – as well as support workers – routine movement is usually *linked* with a routine interaction or activity. If we follow on from Ben’s routine movement as he arrives in the Hall, putting his bag in his locker and sitting at his table, we see a routine interaction across observations as support workers (interchangeable) bring him two bottles of squash so he can choose a drink. Indeed, requesting, offering or providing drinks can be seen as a generalised routine interaction that happens between support workers and inhabitants as they arrive into the Hall (example below) though, as we saw in Ben’s case, the communicative engagement may be uniquely formed to particular inhabitants. The obvious next step here represents a routine activity – the consumption of drinks.

2 support workers speaking to each other – ‘are you at gardening today?’ – ‘yeh’ – ‘bit rainy’ – ‘yeah I have been before in the rain though and it’s not too bad’ – the person she is supporting walks through the front door – ‘morning Charlie would you like a juice’ – ‘yeh’ – she disappears into the kitchen (ethno notes, 12th June).

To take another example, every morning an inhabitant arrives into the Hall and stands silently by their locker until a support worker interacts with them. The inhabitant is subsequently verbally prompted – both with words and his own his personal ‘CHH CHH’ vocalisations - to put his bag away in his locker, after which he kicks his shoes off and they walk over to his personal area of seating. Here, in what appears to be a custom in which the inhabitant seeks assurance to sit down, the two exchange physical gestures, hisses and further ‘CHH CHH’ vocalisations (some support workers were also observed vocalising a 3, 2, 1 countdown). The inhabitant then proceeds to change his clothes to which the support worker conceals him with two large mobile screens. This daily occurrence features routine movement (enters Hall, waits, moves across Hall), interaction (prompts to put bag away, kicking shoes off, physical gestures, ‘CHH CHH’ and vocal exchanges) and activity (putting bag away, change clothes, positioning screens) that forms a larger routine shared between the inhabitant and support worker (see fieldmaps below, Figure 22).

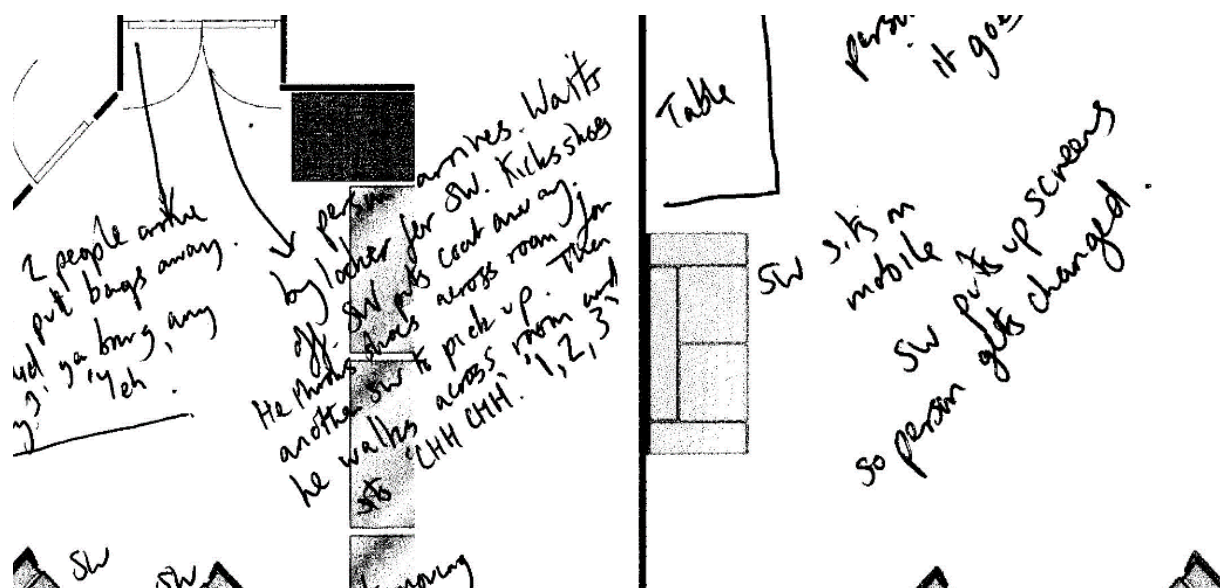


Figure 22: Extract of fieldmap showing routine interaction, movement and activity of inhabitant. Text reads: 'person arrives. Waits by locker for SW. Kicks shoes off. SW puts coat away. He throws shoes across room for another SW to pick up. Then he walks across room and sits "CHH CHH" "1,2,3" – "SW sets up mobile screens so person gets changed"' (fieldmaps, 19th August, 9.10 a.m.).

Just as routine movement represents an activity for two inhabitants, another uses routine interactions as an activity shared with support workers – walking into or through the Hall and asking them to repeat music related phrases such as 'You already have an Elvis one' (ethno notes, 21st May). These interactions can become unique to him and particular persons, I for example was frequently asked to repeat a 'Little Richard, Chuck Berry' phrase (fieldmaps, 12th August, 10.00 a.m.) which I never observed being asked of any other persons. Although this routine interaction/activity has temporal connotations in that the inhabitant often initiates it during times in which he arrives at or departs from the Hall, it also appears to happen arbitrarily through the day as he appears from his personal darkened room. In this way, the Hall's sense of day-to-day routine is at times evident in recurring events that lack specific timestamps and hold no particular positions in its usual proceedings; one may expect them to happen when the relevant inhabitants are present, though precisely when may be less predictable.

Further 'business as usual' events were observed in an inhabitant who regularly walks around the Hall and gently high fives support workers (fieldmap, 15th July, 10 a.m.), as well as the aforementioned wandering inhabitants who sings and speak (fieldmap, 20th August, 11.40 a.m.). Suggesting that these routines have connotations to them that a person new to the Hall may not understand, a support worker

said of the singing 'it's hard to believe that's happy' (ethno notes, 21st May); comparably, the phrases of the talking wanderer may also appear alarming, 'don't hit me. Now come on. Calm it down. Don't swear please. Come on. I'll thump you if you swear' (ethno notes, 11th June), though prompt no response from support workers. Learning how these routines relate to individuals – whether they are something to ignore, stoke attention or respond to – is therefore important for people new to the Hall and, as observed when an agency support worker loses track of a wandering inhabitant (fieldmap, 20th August, 13.10 p.m.), can provoke action if misunderstood.

Support workers do not only respond to the routines of inhabitants but also have their own that relate to their day-to-day responsibilities and the temporal structure of the day. As previously mentioned, providing food and drink appears to be ingrained in the everyday activities of support workers, happening consistently during mornings and lunch periods and observed as linking with the routine interactions of inhabitants. This routine appears to have strong temporal connotations for support workers as they are observed refusing food or drink in between the morning and lunch periods (extract below) while imploring inhabitants to eat at lunch – 'you must eat your lunch, come and sit down' (ethno notes, 15th April).

Mary's (inhabitant) support worker sits next to me and Mary walks ... Mary leans in close to her support worker's face and rest her cup on their shoulder, 'you've just had a coffee' says the support worker and Mary walks off' (ethno notes 11th June).

Similarly, as support workers discuss support stories during the early morning bustle, they prompt arriving inhabitants to put their bags away or, if ignored, do it for them (ethno notes, 10th April). Although these temporal patterns may direct support workers towards what they should be doing at particular times (there were no observations of support workers being told to do these things by colleagues), an occasion in which Ben became distressed when a support worker attempted to write in his communication book (lifeworld notes, 15th April) – a routine responsibility for support workers when supporting a person – shows that following the temporal flow can disrupt the individualised routines of inhabitants. Thus, similar to the way in which space is prioritised less for support workers than inhabitants, the Hall is generally a place in which day-to-day life is governed to greater extents by the individualised routines of inhabitants than that of the general responsibilities of support workers.

When brought together in regular temporal patterns, the routine activity of some of the Hall's people can act as a source of interest for others. The talking, singing, wandering inhabitant for instance is seen to inspire others to join in or jovially respond to his comments (example below), while his ability to eat hot food is a talking point each Tuesday lunch time (fieldmaps, 13th August, 12:50 p.m.).

One of the men walking up and down says 'oh ok stop swearing. Oh give it up now don't swear please.' Anne says to me 'I can see his mother coming through' (ethno notes, 11th June).

The same person's routines also causes frustration for another inhabitant who makes negative vocalisations whenever they talk or walk in proximity, leading to attempts by support workers to try and modify the routine (ethno notes, 11th June). Observing the routine activity of one inhabitant has for Ben become a routine activity of his own, watching a person complete jigsaws each Wednesday morning:

He puts his fingers in his ears for 10 seconds then crosses his arms and begins to observe the man doing the jigsaw. He watches intently, occasionally putting his fingers in his ears but keeping his eyes on the jigsaw. He smiles for a few seconds... (lifeworld notes, 3rd April).

Being part of the Hall's day-to-day life does therefore mean that, at times, the routines of support workers and inhabitants naturally shape to one another, helping to define what they do on a regular basis.

Through day-to-day repetition, the Hall's routines appear to generate an expectancy of events in its people – to greater or lesser extents, they know how others will act, move and interact and so have a sense of how their own day will plan out. This is most clear in the actions of inhabitants, for example the person who waits by his locker for a support worker to greet him or when Ben turns on plug switches in anticipation of a support worker later providing him with a laptop. These routines have little to no directive communication – the person does not ask for a support worker to greet him, they just wait until it happens and, likewise, Ben switches the plug on during art and a laptop is provided once finished. In these examples, both support workers and inhabitants have an understanding of the routine and act accordingly. When support workers do use directive communication, it is often in relation to the broader temporal structures of the service such as lunch times or when a session is beginning, though, as we see in the below example, this does not always prompt a response:

The man jumping on the spot is told by his support worker that it is time to get the bus though he ignores her. The man is quite loud and the support worker looks slightly frustrated when asking again and being ignored again. (ethno notes, 2nd April).

Expectation of day-to-day life is thus maintained through the repetition of activities, interactions and movements – loosely tied to a pre-defined schedule - that brings people together across particular time periods and gives an ongoing sense of future for those involved.

6.16 A sense of risk

This theme details how The Hall as a space represents an interesting dichotomy between a place of risk and a place of safety. Support workers are the primary managers of risk, using their understanding of the Hall's people and customs to identify and respond to risk in order to create a safe place in which to live and work. As knowledge and experience of the Hall changes from person to person, risk is perceived by support workers in different ways. It is an ongoing presence that is produced through frequent discussion - beginning when support workers arrive in the morning – and that they primarily locate in the activity and character of inhabitants in order to share ways of working on a day-to-day basis.

6.17 The creation of risk

To begin, it is important to point out that support workers are asked to read an inhabitant's risk assessments prior to supporting them; so, for instance, Ben's assessments outline the risk of travelling with him in a car and the risk of aggression when engaging with him. Thus, whether they understand it to be a valid assessment or not, support workers are presented with risk as an inevitable part of their role. Furthermore, as the Hall is a busy space with numerous inhabitants coming and going - with support workers not necessarily knowing each person and their related risk assessments – it becomes a place of unknown risk that fluctuates in relation to which support workers and inhabitants are present. We see this evidenced in a conversation between two new support workers who are sitting and reading risk assessments in the Hall:

'...you read through them, plan it and then it's changed... If your with another person (Support worker) it doesn't matter too much but if your by yourself you need to know them (risk assessments)... the first week you're on your own is really scary' (ethno notes, April 15th).

Here is an expression of doubt relating to the perceived risks of working with inhabitants. Specifically, the support worker is communicating to another that a lack of understanding of risk creates worry as you first begin support though this can be reduced if working with a more experienced colleague. During the fieldwork, Ben's support workers would express concern that they had not worked with him many times before (ethno notes, 15th April) and, on one occasion, asked not to be observed as they were anxious about meeting him. Elsewhere, a new support worker struggling to read through the risk assessments of a person they are about to support is told by a long standing support worker 'probably just make sure you read accessing the community and physical aggression (two particular risk assessments)' (ethno notes,

15th April) – a statement from experience about where risk resides with a particular person. Perhaps then, the absence of Hall experience exacerbates a general sense of risk that staff perceive to exist when engaging with inhabitants though, over the course of time, this either becomes more clearly defined or understood as insignificant.

The presence of support workers with greater support experience means that the Hall represents a place of reduced risk than when compared to day service life outside of its parameters. That is to say that many of the Hall's inhabitants leave to pursue projects elsewhere, such as when Ben goes to the cinema, and this isolation from the Hall represents a risk that support workers appear to discuss more than any other. This may include experiencing overwhelming crowds (ethno notes, 10th June), judgemental public (ethno notes, 3rd April), aggression (ethno notes, 1st April), ill health (ethno notes, 21st May) or boredom (ethno notes, 3rd April). One frustrated support worker noted that absence from the Hall risks losing support from senior support workers and management:

Ann (SW) returns to talking about problems with the service and how the support workers don't get the support that they need. I ask if she brings this up in her supervisions and she says 'what supervisions?', saying that she doesn't have the time for them as she is rarely in the day service (she mainly support people outside of the physical building) (ethno notes, 12th June).

That being so, the Hall acts for some as a type of haven to protect from the perceived risks of daily life outside the service; it is a safe place in which to keep track of inhabitants and assess the risk of taking them out (see below fieldmap, Figure 23). Even leaving the Hall to have a walk in the car park – as a few inhabitants do regularly – is not allowed for one person whose support worker is perhaps unsure of the potential risk of outdoors (ethno notes, 28th May).

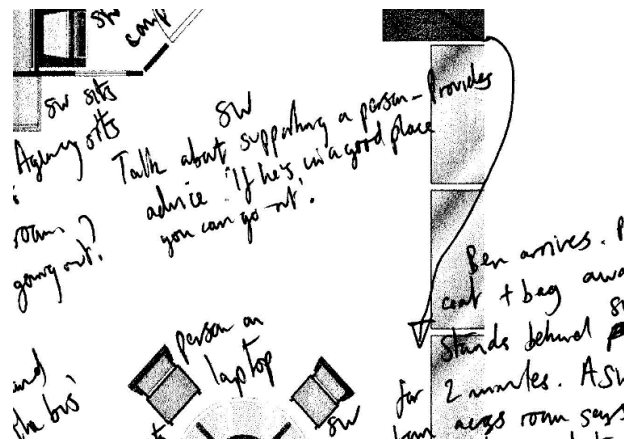


Figure 23: Fieldmap showing support worker instructing another to assess mood of inhabitant before leaving Hall. Texts reads:

‘SW talks about supporting a person – provides advice “if he’s in a good place you can go out”’ (fieldmap, 19th August, 9.50 a.m.).

While the Hall may represent a secure place to live and work, it too carries its own sense of risk that is evidenced in observations of day-to-day life. As with risk outside the Hall, support workers regularly discuss its potential inside before making plans to reduce it:

They talk about how another service user is rude about people at times and that they tell him not to be. And how another service user will throw items at them and that they will smack you if you get too close to them and that if she gets like this you need to swap with another member of staff... (ethno notes, 21st May).

At times support workers act in ways that attach a sense of risk to a situation or inhabitant, signifying that the circumstance requires a support worker with particular experience or attributes. In the below example a few support workers decide not to greet an inhabitant – one says that they have a poorly shoulder while the support worker that does say hello clarifies that the rest have not worked with him before – suggesting first that there is a risk that the inhabitant exacerbates physical injuries and second that there may be an innate risk in engaging with him without previously supporting him.

A few congregate in the kitchen, talking Game of Thrones and how to support someone swimming. One young man (service user) comes in and waits by his locker – I know that he waits until staff greet him before he puts anything away. 1 staff member who was talking to me asks if anyone can support him to sit down but no one answers. He walks over towards the young man and one support worker says ‘I can’t – my shoulder’. The support worker says ‘so have none of you ever supported him’ and they all say no. He says hello to the man and prompts him verbally to put his bag in his locker. (Ethno notes, 28th May).

Elsewhere, the Hall environment becomes a risk as support workers are seen to shout in to ask people to clear away bags when a particular inhabitant is arriving (fieldmap, 20th August, 11:40 a.m.) or –

as seen in the 'space management' theme – check inhabitants moods before allowing entrance to the kitchen (ethno notes, 10th June). Engagement between inhabitants is also monitored and mediated for risk with support workers defining how they can interact with each other (extract below), monitoring their movements and separating them if they feel a risk is posed (lifeworld notes, 17th April).

The service users says 'Ben is my friend – can I say hello?' His support worker says 'shake hands but no cuddles'. He moves close to Ben and puts his hand out, they touch hands (ethno notes, 16th April).

If there is a heightened sense of risk - as seen in the conversation and actions of support workers when an inhabitant is throwing food out of the staff office (ethno notes, 8th April) – support workers gather to support each other and share words of advice. Risk thus becomes ingrained in the Hall's daily activity. It is highlighted so as to minimize it but by corollary leads to an increased awareness of it.

The regard for support worker experience in reducing risk or responding to it appropriately means that inconsistency in staffing – such as staff turnover or rota changes – becomes talked about as itself adding to risk in daily life. Support workers were regularly observed talking about staffing issues and how this created risk, with some also communicating directly to me about particular problems they faced. For instance, a long standing support worker said that the introduction of new staff resulted in those with greater experience having to face 'more challenging sessions' (ethno notes, 12th June), suggesting that while experience may be seen to reduce risk it also increases one's exposure to it. There does not appear to be any rules as to when to discuss staffing issues – it is part of daily activity across the Hall and was evident even while support workers supported inhabitants (ethno notes, 21st May). By linking risk with staff changes and inconsistencies, it further becomes part of the inevitability of daily life at the service as the organisation has to reposition support workers to respond to the support needs of inhabitants. As shown in the below example, this can become overwhelming and may result in a desire to leave the Hall:

A young support worker is asked 'have you handed your notice in?' by another support worker. She says that she has and that she will be leaving by the end of the month, she says that she 'can't take it anymore' that the job is too 'unpredictable'. She doesn't have another job lined up but she has to 'get away'. (ethno notes, 10th June).

Although we see that the sense of risk found in the Hall's day-to-day life can have negative consequences, it also appears to instigate ways for support workers to anticipate and act in different situations. In doing so, the Hall simultaneously becomes a place of safety and comfort, particularly for

inhabitants. Ben for example appears as though he sees risk as embedded in the unknown nature of change and if confronted by this – perhaps with a difference in the order of activities – he can experience intense apprehension. Support workers are aware of this, responding to minimize risk for Ben by instructing each other prior to supporting him so that they provide a generally consistent routine. Commonly, another inhabitant confidently enters the hall in the morning as they stroll through to their personal seat (fieldmap below, Figure 24), handing their lunch to service staff on the way, yet leaving the Hall is fraught so much so that on one occasion they pull their support worker over to avoid departing (extract below); here it seems that the Hall represents security for the inhabitant and risk to the support worker, while outside is the opposite case.

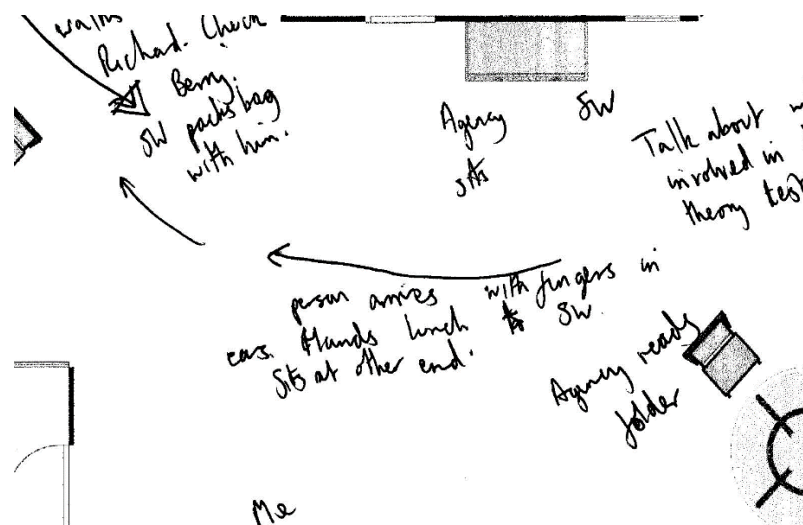


Figure 24: Fieldmap showing an inhabitant arriving, strolling through the main Hall while hand their lunch to a support worker. Text reads:

‘person arrives with fingers in ears. Hands lunch to SW. Sits at other end.’ (fieldmap 12th August, 10:00 a.m.)

A support worker walks towards the exit and the person she is supporting comes running around the corner and pulls her back by her arm. She says ‘it’s time for horse riding’ though he returns back to where he was sitting. She repeats this 3 times and on the third he pulls with a bit more force and she falls over... (ethno notes, 21st May).

A sense of risk that is so often evident in support workers’ actions does perhaps then mean that inhabitants can experience a dependable day-to-day life in the Hall. By overemphasizing risk in many regards, support workers by necessity draw attention to areas in which it is also perceived by inhabitants,

such as Ben and changes in schedules, leading to ways of acting and behaving that are congruous with the perspectives of those they support. As such, the atmosphere of risk leads to practices of both exclusion and inclusion. By highlighting risk through discussion, mediating the actions of inhabitants and support workers, communicating worry aspects of the job and relying on experienced support workers for guidance, risk appears exaggerated for the Hall's staff in order to reduce it for the Hall's inhabitants.

6.18 A place to learn; a place to teach

This theme discusses the pedagogical character of daily life in the Hall and the purpose it serves. This is a continual process of teaching and learning for support workers, assisted by each other and through the experience and guidance of inhabitants. During the three periods of fieldwork at the service, this was a constant and frequent feature of their talk and actions, beginning as they arrived in the morning and continuing throughout the day. To greater or lesser extents, it appears to be synonymous with all support workers that enter the Hall as they switch between the role of teacher and learner depending on their experience with inhabitants. Two methods of teaching will be explored: first, an impersonal method that works to ensure the day-to-day running of the Hall by providing explicit direction to support workers, and second, a personal method that draws from the histories, personalities and experiences of the Hall's people to help support workers understand their daily roles and that creates a shared sense of community.

6.19 Teaching and learning in the Hall

Because the Hall is a place in which support workers gather through the day, there is always the potential for exchanges of advice or knowledge. This potential is realised most notably as the day begins, when there is the largest gathering of support workers. Here, the lack of inhabitants provides time and space to teach and learn. This period can be understood as a vital part of the support workers' day-to-day teaching calendar: they do it without question, whether colleagues ask for or require information, talking seamlessly between personal and professional life:

The room has multiple conversations from support staff discussing both person and work related things. Some reading service user folders, some eating breakfast, some on laptops. One support worker is diagnosing the parents of those they support as autistic, another comments 'well it is genetic'. One says to another that they have been put down to shadow a session, the other responds saying 'this is so you get used to

how to do it... she (whoever done the rota) also put me down to do him.' (ethno notes, 8th April).

Through this, teaching and learning surrounds support workers as soon as they arrive. It is interweaved into social interaction so as to not join in would place a support worker outside of convention, not just as a support worker, but also as part of the Hall's social life. One should note that as the process of fieldwork embedded me into the Hall's everyday life, its pedagogical character also reflected on my own position as support workers looked to me to learn of aspects of Ben's support (below), and, on another occasion, I found myself providing occasional, unsolicited direction (lifeworld notes, 2nd April).

As I had been along with Ben the previous two weeks, she asks questions about what happens – whether he still goes for a drink afterwards and if he still likes to go on a particular machine (ethno notes, 15th April).

Learning in the Hall can be understood through the scope of five teaching methods: storytelling, casual conversation, verbal guidance, showing and self-teaching. The first two focus on personal experience to increase general knowledge of the Hall's people, activity and history, while the others are directive, working to prepare support workers for future events. So in one storytelling instance (ethno notes, 12th June), a support worker pleasingly tells a manager how an inhabitant had rejected the idea of a walk and instead, after being asked what they'd like to do, chose and enjoyed an afternoon of bowling to which their mum was 'totes emosh' (very emotional). Here, the story informs of the inhabitant's ability to make choices and their positive experience of a particular activity, it acts as a guide for other support workers on occasions when the inhabitant does not want to walk and it shows how these actions can positively affect the inhabitant's mum. Although the support worker makes no reference to the point of the story – they just begin telling the manager on meeting in the Hall - the manager sees that it may offer a valuable lesson to other support workers and asks 'do you want to tell the other staff?'. The support worker presents a narrative with conflict and resolution that offers interest whether one knows the inhabitant or not. Storytelling thus offers a non-intrusive teaching method in that it is not explicitly directive and, as I observed when a support worker talked to me while supporting Ben (lifeworld notes, 16th April), can be interwoven with stories from support workers' personal lives.

Teaching through casual conversation works similarly to storytelling in that support workers use it to socially engage with each other even though it focuses on work based issues. Through this regular interaction, casual conversation provides ongoing updates on the service: significant events, how service people are, future plans or problems to be aware of. These small exchanges of knowledge help support workers to keep up with day-to-day developments in order to learn how they and others may need to

respond. The temporal and spatial character of the Hall enables and encourages this as transient staff – coming and going from the service across the day – bring new insights for others to learn from, such as a support worker who, while supporting Ben in the Hall, helps to explain to another passing support worker that the inhabitant they are supporting may be in a frosty mood due to ill health (ethno notes, 21st May). Indeed, teaching others about the reasons for inhabitants' moods is a regular feature of support worker conversation (example below), though we also see information shared on inhabitants' music tastes and food habits (ethno notes, 16th April, 15th April) as well as lessons that focus on staffing issues (ethno notes, 28th May) and places to visit (ethno notes, 10th June).

Peter says to me that Ben is doing the same as last week but speeded up (I haven't noticed a difference). He says that 'this is because' and mouths 'things are going bad at home' (ethno notes, 9th April).

Teaching as an intrinsic part of day-to-day support worker interaction – enacted through storytelling and casual conversation – thus it allows support workers to learn without the need for structured meetings or any official organisation. This is evidently important for support workers whose roles rely on them being able to understand the day-to-day thoughts and feelings of inhabitants, which, as with any other person, will change in line with their ongoing life circumstances.

The other three teaching methods - verbal guidance, showing and self-teaching – occur when a support worker feels that a colleague, or, they themselves, need to learn something particular about their roles. Verbal guidance is when a support worker tells another something they should do, while showing is when a support worker demonstrates what another should do. They are directive, tending to instruct support workers to act in specific ways, such as how to engage with a particular inhabitant (ethno notes, 21st May) or paper work they need to complete (lifeworld notes, 15th April). Such teaching was also provided to me in relation to both Ben and other inhabitants (who I had not and did not meet):

Ian mentions that Ben doesn't like much chit chat (he has said this numerous times before to me during Gym sessions) and compares him to another service user.... He says that a service user has a distinct route when going to the local library and how he has to ask taxi drivers to be quiet if they talk too much as the service user doesn't like it... (ethno notes, 21st May).

One should note that inhabitants also use these methods to teach their support workers – Ben for instance regularly guides support workers through his afternoon of art (lifeworld notes, 9th April), while another inhabitant makes sure a support worker is informed as to where bags should go (ethno notes, 10th June).

Self-teaching is when a support worker learns what to do from paper or electronic documents, such as communication profiles, risk assessments or session plans (instructions on how to support someone to do a particular activity). It is in some senses a lesson one must take before engaging with an inhabitant as demonstrated when a manager quickly collects then hands Ben's folder to a support worker who had just been introduced to him for the first time (fieldmap, 16th July, 13.00 p.m.). These three teaching methods are primarily concerned with the immediate future - as we see quite literally in the example below when a support worker completing an art piece with Ben is instructed by another on how to work with Ben during art:

Another support worker comes over and says to Jill 'oh you shouldn't be doing it like that' – referring to how she is ripping tissue paper for Ben. He says 'you should give him each piece rather than leave it on the table'. She starts doing this... (ethno notes, 16th April).

The Hall thus acts as a place in which support workers can gain the necessary day-to-day knowledge to fulfill their roles, teaching themselves and others in order to understand their specific schedules and responsibilities.

6.20 Teaching to create community

What is salient about the teaching methods of the Hall is the dichotomy between the personal – as seen in storytelling and casual conversation – and the impersonal – as seen in verbal guidance, showing and self-teaching. Support workers are in a roles that involve engaging closely with inhabitants on a one to one basis, sharing in their day-to-day lives. They are initially shown how to do this in an impersonal way as part of their positions as support workers - see for example, an extract from Ben's art session plan:

Once you have drawn a shape, put some glue in one spot and give Ben some small pieces of tissue paper. Ben will scrunch these up and place them where you have put the glue. Continue to repeat this until roughly 2.30 p.m. or the shape is filled. If Ben appears anxious or appears to be getting bored of the activity, conclude the session... (Ben's art session plan).

These impersonal methods emanate from the client-professional relationship that exists between support workers and inhabitants and that the service instills through training and paperwork. However, as we saw in the earlier story concerning an inhabitant going bowling and their mother's reaction, the inevitable experience of support work means that they learn of inhabitants' lives in rich and complex ways – the ebb

and flow of their day-to-day lives, the intricacies of their personalities, their histories and their families and friends. This knowledge can enable support workers to create personalised ways of engaging with inhabitants, yet it involves a sensitivity that is at odds with the impersonal teaching methods that direct support workers through their day-to-day roles. By sharing it through stories and casual conversation, as is so common in daily life in the Hall, support workers come to know and relate to inhabitants in personal ways without challenging their positions as 'service users'.

As mentioned, impersonal teaching methods seek to maintain specific ways for support workers to work with inhabitants on a day-to-day basis and, for instance, is evidenced in the numerous times that Ben's support workers informed me that he does not like 'too much chit chatter' (ethno notes, 1st April) and how they automatically offer him a choice of drink with two bottles of squash when he arrives in the morning (lifeworld, 15th April). These types of lessons are given to all support workers who enter the Hall – so, when a temporary agency support worker arrives, they are given the folder relating to the inhabitant they are due to support along with some brief instructions from a manager (ethno notes, 28th May). However, teaching through personal methods is not provided in the same manner, with agency support workers rarely involved and at times seen to be excluded through spatial separation from service support workers, as seen in the below fieldmap (Figure 25):

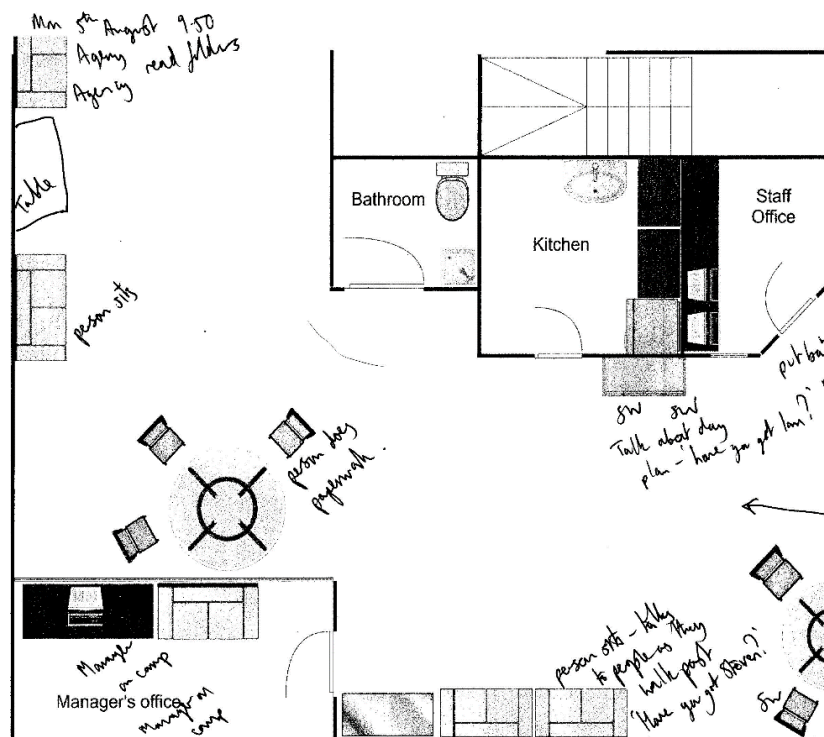


Figure 25: Fieldmap showing agency support workers sitting separated in the top left corner reading inhabitant folders,

while inhabitants and service support workers sit and talk at the other end of the Hall (right hand side) (fieldmap, 5th August, 9.50 a.m.).

Newly employed, permanent support workers are treated differently, introduced to inhabitants through casual conversations (ethno notes, 1st April), told stories about them (ethno notes, 16th April) and advised that they need not learn parts of inhabitant's folders (ethno notes, 15th April). It may be that as agency support workers are temporary, day-to-day life dictates that they only need to learn what is required for that specific day while in depth, personal knowledge of inhabitants is withheld. In contrast, new service support workers are seen as deserving of greater effort, invited into the Hall's daily life through personal teaching methods that embeds their roles within the context of a community.

To learn through storytelling and casual conversation, support workers seek to go beyond the routine and responsibilities of everyday life by sharing in the experiences of inhabitants and other support workers. By granting access to knowledge of the Hall and its people, support workers with greater experience offer membership to its community. The everyday conversation, detailed below, seamlessly switches between personal and professional life and in doing so demonstrates this sense of inclusion: support workers are learning about the Hall's people while contributing parts of themselves.

There are 12 support workers sitting around two tables. On one table, they talk about hair removal and the pain of waxing. A service user who had been in the loo comes out and sits down between them. The chat continues – talk flits between who they are supporting that day – what they are planning on doing – things they did at the weekend. More service users arrive, it is quite busy with around twenty people (ethno notes, 15th April).

Inhabitants also have ways to extend this community invitation, high fiving support workers (ethno notes, 9th April), involving them in exchanges about blues music (fieldmap, 15th July, 8.50 a.m.), tickling their ears (ethno notes, 9th April) and greeting each one individually with 'good morning Mr. (their name)' (ethno notes, 10th June). Joining the Hall's community brings benefits: one support worker in ill health comments to a manager 'I woke up this morning and I weren't going to come in, but you know what? Being out and about with people this week has made me feel so much better' (ethno notes, 10th April); while for another it provides relaxation (ethno notes, 3rd April) and happiness (ethno notes, 12th June).

The daily effort attributed to bringing support workers into the Hall's community is noticeably greater than that given to inhabitants, reflecting the transient nature of the former and the permanent

nature of the later. So on the one hand, as support workers are seen to come and go from the Hall's community – discussed by them as part of the inevitability of day-to-day life (ethno notes, 10th April, 1st April, 10th June, and 22nd May) – there is a continuous need to invite new members through the teaching methods I have described; while on the other hand, the infrequent occurrence of inhabitants joining or leaving the Hall's community – I observed this once during four months of fieldwork – means that they are accepted as part its history and future. As inhabitants are the foundations of the community, teaching new comers about their distinct characters and experiences is central to maintaining a sense of place that has grown and developed over time through the contributions of a group of people. However, the idiosyncratic communication of many inhabitants leaves the need to share this as entrusted with support workers, positioned as narrators and chroniclers of the Hall who pass down its identity through day-to-day talk and conversation. One can understand this as an oral tradition specific to the Hall, animating the diversity of life and experience that happens on a daily basis but that is mainly absent from official documentation.

A support worker starts to tell me how they are going swimming with a man today and that he has a clothes washing ritual after the swim and that the previous week he had ran out of the changing rooms naked to see the lifeguard (they have become friends of sorts after swimming there a while). He says that thankfully the staff are really positive and understanding (ethno notes, 22nd May).

On the surface, teaching and learning in the Hall appears to be a way for support workers to navigate their ever changing day-to-day roles. It directs both new and old towards shifts and developments in the Hall's routines, shining a light on significant events that may affect how they need to work while creating consistent ways for staff to engage with inhabitants. Below the surface though, teaching and learning utilises storytelling and conversation to overcome the prescribed impersonal nature of the Hall in order to bring together and maintain a community that exists through the shared lives of inhabitants and a transient support worker team.

6.21 A summary of the findings

In the first part of this chapter, Ben's experiences of everyday life at the day service were explicated through three central themes. These are key aspects of Ben's lifeworld, felt within the situations he finds himself in while at the day service. Described were ways in which Ben experiences himself as the supported, the supporter, the independent and the partner. These experiences are part and parcel of his

role within inhabitant-support worker dyads, though demonstrated were Ben's assurance in his own activity, and his keen interest in others, extended out through modes of communication known as polite and comfortable. The significance of Ben's embodied experiences were then detailed, as relating to his sensory perceptions and through the activities he pursues, and the busy social life he is situated within. This significance related to the exhilarating nature of the experience, evidenced, for example, at the cinema and at the laptop, but also in the vulnerability in being surrounded by unpredictable support workers. Leading on from the notion of (un)predictability, the final theme described the ways in which Ben draws from his past to ensure a safe and comfortable future. This includes preparing others for what is to come, that which has been experienced before, and how, for Ben, these aspects of time, space and sociality instill a sense of belonging.

The second part of the chapter detailed the broader phenomenon of everyday life at the day service, explored through its main gathering space, the Hall. The spatial customs of the Hall were shown to provide ways of managing space with minimal effort. This included the Hall's people adhering to a space hierarchy, providing some with personal areas and controlling the fluctuating population seeking to use its space. Instilled within these spatial customs were forms of action, interaction and expression, as relating to individuals, such as the two inhabitants who regularly walked back and forth, and groups, such as in conventions around refreshments. Relating to the actions, movement and activity of the Hall, was its unwritten routine that gave the space a sense of expectancy. Inhabitants and support workers provided and followed queues, instilling a sense of business-as-usual into the diverse habits and practices of everyday life. The creation of risk was detailed as a practice of support workers, and though the aforementioned customs of the Hall were seen to reduce this, risk was seemingly exacerbated when support workers and inhabitants left its space to explore interests or activities in local areas. The chapter concluded with a description of the pedagogical nature of everyday life within the Hall. It was a space for support workers to learn, as facilitated through teaching from inhabitants and fellow support workers. Key to this was an impersonal teaching method involving stories of inhabitants' lives and personalities, as these everyday interactions maintained the history and community of the Hall.

Chapter Seven - Discussion

Service Culture and Place Ballet and the Possibility of At-homeness

The first part of this chapter addresses the fourth objective of this research: to situate the roles and experiences of autistic people with profound learning disabilities within a broader understanding of day service culture, that which includes the cultural contributions of service people, support workers, and formal authorities (e.g. managers, researchers and policy makers). To do this, it will draw from the findings presented in the previous chapter, those concerning Ben's everyday experiences of day service life (Chapter Six Part One), and the phenomenon of everyday life within the Hall (Chapter Six Part Two). As established in the literature review (Chapter 2.6), day services in this research are being viewed as semiospheres: spaces that are defined by the interaction of language and symbols that, as such, are demarcated by cultural and social values, but that also holds cultural and social values (Nöth, 2015). As Lotman (1990, p. 125) describes, 'semiosphere is the result and the condition for the development of culture.' In the context of this research, this was analysed through the phenomenological scope of 'place ballet', that is, the semiosphere of the service fosters place ballet – through the way space and activity has come to be organised – but the day-to-day events of this place ballet also contributes to the semiosphere. For Seamon (1979), a successful place ballet promotes the essential experiential structure of rest - *at-homeness* – 'the usually unnoticed, taken-for-granted situation of being comfortable in and familiar with the everyday world in which one lives and outside of which one is 'visiting', 'in transit', 'not at home', 'out of place' or 'travelling' (p.70). Service culture has the potential to foster or suppress the characteristics of at-homeness for its participants, though this will depend on the ways in which contributions of inhabitants, support workers and formal authorities are realised. The following discussion will therefore look at how aspects of service culture, including the everyday contributions of autistic people with profound learning disabilities, affect place ballet within day services, drawing from the previous chapter's analysis and wider research to explore how this may cultivate the experience of at-homeness. To begin though, a definition of at-homeness and its five characteristics is provided.

7.1 *At-homeness*

To expand on the relationship between day service culture, place ballets and at-homeness, it is first useful to refer to the concepts of *movement* and *rest* (Seamon, 1979). Movement concerns body-subject and feeling-subject – the taken-for-granted ways in which our bodies learn to move and feel in the world. To begin, we must consciously pay attention to how we move and feel in situations, though over time and

through repeated movements, our bodies no longer require our conscious attention, creating ‘time-space routines’ with which to move through our daily existence (Seamon, 1979, p.55). In essence, if a time-space routine is changed, the body-subject and/or feeling-subject is confronted as consciousness must take over. Movement is in a reciprocal relationship with rest, working to connect points of significance within time-space routines. Rest refers to ‘any situation in which the person or an object with which he is she has contact is relatively fixed in place and space for a longer or shorter period of time’ (p.69). Rest thus roots people to particular spaces over the course of time, stabilising them within spaces in regards to body-subject, and emotionally connecting them through feeling-subject (p.71). Because of their relational aspects, movement and rest both encompass features of one another, and so repetition of movement may come to represent rest to a greater extent – for example, a walk through an unknown park may constitute movement at first, though with repeated visits it may relate more closely to rest.

When time-space routines are consistently shared by people within a fixed site, they form place ballets. The extent to which place ballet functions depends on the space – its rules, customs, dimensions, and so on – meaning that if it cannot accommodate the *movement* and *rest* of its users, it is overpopulated for example, the place ballet will collapse and people will experience frequent confrontation. In functioning place ballets, *rest* is emphasised for participants and they may begin to experience ‘at-homeness’. As place ballets root people’s body-subjects and feeling-subjects to space through shared time-space routines, at-homeness can be experienced both on an individual level and by the ‘totality of participants’ (p.95). At-homeness reveals the ‘significance of place, to feel it, to know and respect its symbols’ (p.92). Seamon (p.78 – 85) describes the experience of at-homeness through five underlying characteristics:

- *Rootedness* – The pull of the place – it organises one’s life through regular comings and goings. Mental energy is conserved as the body-subject and feeling-subject know the space intimately. Things have a fixed place, as do day-to-day schedules and activities – they are taken for granted.
- *Appropriation* – Space is possessed and controlled. Appropriation means the opportunity to be private. If unexpected or unwanted guests come in to it, feeling-subject reacts to the incursion, though friends and close acquaintances may be more welcome. The sense of at-homeness may be lost through an exceptional incursion, such as a burglary.
- *Regeneration* – The comforts of at-homeness offers physical and mental rest. One’s bed is often valued more than any others – those in hotels or friends’ homes do not offer that same sense of comfort. At-homeness provides a sense of security that allows for rest. After a tough day at work, socialising is turned down for it is the space of the home that regenerates.

- *At-easeness* – ‘The freedom to be’ (p.83). The comfort to act and behave as one wants. At-homeness eliminates embarrassment. One can sing out loud, dance, eat chocolate spread from the jar – there are repercussions to such actions if done outside the space of home. At-easeness is sensed through the ways in which space reflects the user’s character - pictures on the wall reassures some who they are, though a tent in the wilderness may be more appropriate for others.
- *Warmth* – The atmosphere of home is friendly and supporting. It feels cosy. Certain areas may emphasise warmth – where the dog sleeps in the conservatory, or a lively dining room. If spaces are unused, they lose their sense of warmth. Places that are warm encourage users to care for them. Effort is put into maintaining its physical qualities – it is nurtured.

Drawing from each of these characteristics, the findings from this study, as well as wider research into services for autistic people with profound learning disabilities, will be discussed to explore how day service culture may promote the experience of at-homeness for inhabitants.

7.2 Rootedness

The space of the Hall gathered people pursuing divergent activity – it was the point at which time-space routines could congregate. The importance of this was most vivid for Ben as he so relied on the consistency of space with which to orientate his days. He pursued the safety and assurance of the temporal and spatial context of his past – that which is rooted at the day service and evidenced each morning – ‘Ben arrives and puts his bag and coat in his bag and sits down at the same table as the previous day... He puts his fingers in his ears and smiles’ (lifeworld notes, 2nd April). This was not just true for Ben though, as both inhabitants and support workers mark the significance of the Hall through their habitual comings and goings that follow the unwritten ‘routine of daily life’ (Chapter 5:15). *Rest* had become a part of the Hall’s life as the activities and interactions were expected, placed within the spatial schedule of everyday life. This schedule reflected the habits, interests and pursuits of inhabitants, rather than that which was defined by the service organisation, signifying a contribution to service culture that has occurred over many years.

Within the established routine of the Hall, inhabitants could develop time-space routines outside its boundaries – relative to its ‘location in terms of paths, places, people and things’ (Seamon, 1979, p.75). For Ben, this instilled a confidence and assurance in leaving the Hall as he was so certain to that which awaited him within the intricate time-space routines of his day-to-day. Each one started and finished in the Hall’s space and so it provided a foundation to realise ‘community inclusion’ in local areas – a key

value of formal culture (see Wiesel & Bigby, 2014) – while also forming a strong sense of rootedness to the space of the day service. For support workers though, leaving the Hall was seen as less predictable, less manageable than life inside its walls (Chapter 5:17) – as one support worker stated, it was only safe to leave with an inhabitant if they were ‘in a good place’ (fieldmap, 19th August, 9.50 a.m.). Important here was the vulnerability of support workers – they represented a transient population that appeared to seek rootedness but were denied it through staff shortages or changes – problems that arise from formal culture. Bigby and Wiesel (2015, p. 315) note that ‘support workers are given little guidance’ when working in public spheres, faced with dilemmas as to how to instigate day-to-day interactions between inhabitants and members of the public. The support workers of the Hall used formal methods of teaching (Chapter 5:19) in an attempt to establish rootedness yet for some the nature of the job was ‘too unpredictable’ (support worker comments, ethno notes, 10th June) and they could not establish the time-space routines required to experience rest.

The informal methods of teaching in the Hall, storytelling and casual conversation (Chapter 5:20), helped to bring new support workers into the community of the Hall, as well as maintaining the histories and events that had shaped its practices. This aspect of service culture was a staple of daily life – communicated through the shared pursuits and expressions of inhabitants and support workers – yet it is a practice that could be seen as incongruent with a formal culture that requires professional boundaries to be upheld. These stories were vivid and full of personality, challenging the assertion that inhabitants are merely *service users* – a position that, for Lloyd (2008, p. 53), ‘does not devolve power or respect – though they were not evidenced in official service documents, such as Ben’s support folder. The communication of many autistic people with profound learning disabilities means that without such practices, their narratives may disappear as support workers come and go. Rootedness ‘requires time to develop’ (Seamon, 1979, p. 81) and so storytelling in the Hall helped to establish and maintain inhabitants’ places within the day service. In turn, this helped to foster rootedness in support workers as their feeling-subjects could adapt to the diverse habits and activity that confronts them – an inhabitant loudly stating ‘I’ll thump you if you swear’ (ethno notes, 11th June) garnered no reaction. It may be understood as a ‘disjuncture between what staff do, and what is formally asked of them’ (Bigby, Knox, et al., 2012, p. 452), which traditionally may be considered a poor service culture, though here shows a consideration for the ways in which inhabitants wish to shape culture.

7.3 Appropriation

The Hall is a place that inhabitants appropriate – the space is possessed by them as their life contexts define its space hierarchy, with some possessing areas more strongly than others (Chapter 5:13). Support workers in contrast represent transient beings, with even their own space – their office – taken over by inhabitants on occasion (ethno notes, 8th April). In one regard, this is constructed through the day-to-day assertions of inhabitants, not only using specific space but also informing others to move out of the spaces they have appropriated, as illustrated in the below fieldmap (Figure 26) with Ben standing behind a support worker until they move from his personal area. This is a crucial aspect of place ballet – that it is ‘in the hands of their day-to-day participants’ (Seamon, 1979, p. 96).

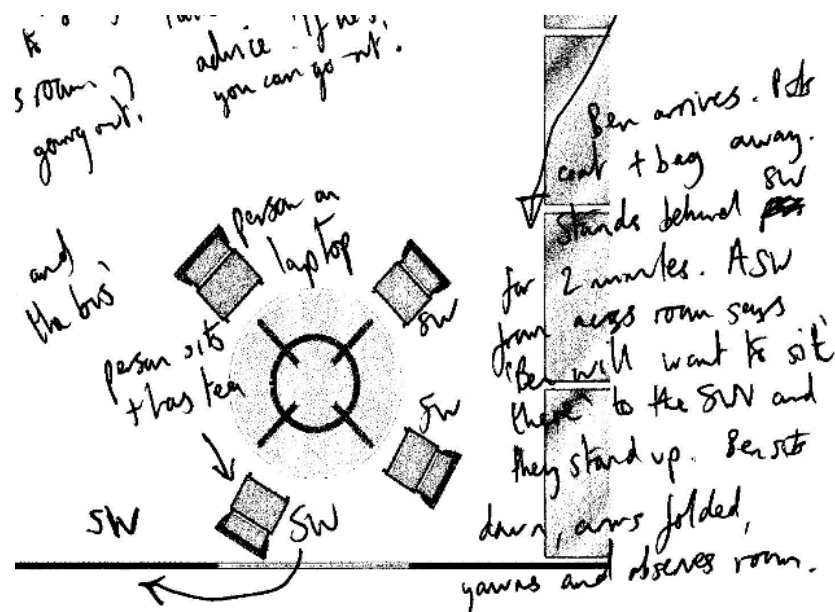


Figure 26: Fieldmap showing Ben controlling his personal area.

Text reads: ‘Ben arrives. Puts coat and bag away. Stands behind SW for 2 minutes. A SW from across room says ‘Ben will want to sit there’ to the SW and they stand up. Ben sits down, arms folded, yawns and observes room’ (Fieldmap, 19th August, 9.50 a.m.).

Appropriated spaces exert control for their proprietors, inevitably leading to the exclusion of others who are required to stay clear or vacate, such as when support workers move inhabitants out of Ben’s area. Similar spatial ownership was reported in an adult day service (Black et al., 2018) whose inhabitants - ageing people with dementia and Down Syndrome – organised one another in regards to particular tables, deciding where new members would sit and who they could socialise with. In both this service and the

Hall, support workers follow the demarcation of space once it has been appropriated by a person, reinforcing the values that inhabitants attach to space. These customs are representative of the autonomy and choice of inhabitants – key tenets of the personalisation agenda (see Morgan, 2010) - and demonstrate the ways in which they can shape the semiospheres of day services according to their own values and interests.

One aspect of service culture that challenged the appropriation of space by the Hall's inhabitants related to the sense of risk that emanated out of support worker customs (Chapter 5:16). There are two areas that risk most affected in relation to appropriation: first, inhabitants did not have full control over their spaces as support workers would often decide who could or could not enter its proximity. Second, particular areas, such as the kitchen, were managed heavily by support workers in order to minimise overcrowding. To take the first point, support workers appeared hesitant to allow inhabitant to inhabitant interactions, so while they were observed leaving inhabitants alone in their personal areas – demonstrating the safety that appropriated space represented - they were also observed moving inhabitants from the table Ben sits at despite him having a keen interest in the activity and habits of others (Chapter 5:13). Space may be seen as appropriated by inhabitants, chosen through their day-to-day habits over the course of time, but their capacity to have guests is limited – seen as too dangerous. The emphasis on risk in service cultures is well documented (see Seale, Nind, & Simmons, 2013), Hawkins, Redley, and Holland (2011) for example draw attention to its contradictory function within residential service policies, finding that support workers are unsure as to how to promote autonomy while reducing risk. The authors (Hawkins et al., 2011) argue that the standardisation of risk assessments leads to generalised practices and this was supported by the actions of support workers in the Hall. It may be that this could benefit from a greater recognition of the positive ways that inhabitants share space with one another, such as the enjoyment Ben had in others hobbies, so to contrast the fear that support workers perceive in inhabitant interactions. Recognising appropriated space formally, such as in support folders, may also help to inform the ways in which support workers understand the spaces of inhabitants and their related etiquettes.

The second impact of risk on the opportunity for inhabitants to appropriate space happened in relation to the capacity of the Hall's space, and this was most exemplified within the kitchen. When the Hall was busy, the kitchen was heavily governed while during quiet periods it was often left open. Entry was not guaranteed – 'we need to be happy before we go in – is Bob happy?' (ethno notes, 10th June) said one support worker to an inhabitant. The wider sense of risk in the Hall was concentrated in the small space of the kitchen, jilting the spatial customs and obscuring the possibility of appropriation by inhabitants. Support workers did appear to want to overcome the spatial dynamics of the kitchen,

including offering a key to an inhabitant in order to gain access during a busy period (fieldmap, 13th August, 12.50 a.m.), but they were also confronted by a kitchen which lacked space. A lack of space in any area, regardless of whether it is a neighbourhood, a business, a café, a school or so on, will lead to the exclusion of certain members at certain times – it is ‘uncontrollable’ (Seamon, 1979) and therefore cannot foster appropriation. As one support worker said of the kitchen while blocking entry – ‘it’s ‘full’ (ethno notes, 11th June). In this sense, the emphasis of risk in service cultures may hinder the extent to which inhabitants are able to appropriate space – thus requiring addressing through aspects of formal culture such as staff training – however this will inevitably be subject to the space that is available within day services as both inhabitants and support workers must adapt accordingly.

7.4 Regeneration

Appropriated space is the catalyst for regeneration as it provides the security and privacy to rest (Seamon, 1979, p. 83). The ways in which small, unexpected events can confront autistic people with profound learning disabilities, as in Ben’s experiences (Chapter 5:6) and many others (see Caldwell, 2017, pp. 96-97), means that space is relied on to offer moments of repose as they encounter their day-to-day worlds. Architectural researchers (Nagib & Williams, 2018; Rapp, Cena, Castaldo, Keller, & Tirassa, 2018) have argued that these spaces require natural light, reduced noise and minimal sensory input – ‘places that feel secure to autistic individuals’ (Rapp et al., 2018, p. 56). Such environmental design was evidenced in the Hall – for example a darker room at one end and a small tent at another – though in general, the Hall itself was bright and busy with inhabitants not necessarily conforming to the tropes of their diagnostic label. Here, where the diverse perspectives and experiences of inhabitants congregate, value was placed on the consistency of schedules to provide respite – those that have proven effective in the past. As these worked for inhabitants, they also worked for support workers, and so *movement* turned to *rest* - as in the two inhabitants that strolled in and out of the Hall with abundant frequency (see fieldmap below, Figure 27) - and inhabitants were able to pursue their interests and pursuits without confrontation, in the ways that had come to be known and accepted by the wider community (Chapter 5:14)

Challenges to regeneration came in the overall temporal schedule of the Hall – that which was defined by formal culture and consisted of activity, lunch and break periods – as occupations could be unnecessarily undertaken or emphasised by support workers, such as attempts to persuade a man to sit and eat lunch. This is what Bigby, Knox, et al. (2012, p. 458) may refer to as a ‘misalignment of power-holder’s values’ though they are referring to support workers not adhering to direction from formal authorities, while here support workers are not adhering to the direction of inhabitants. The more

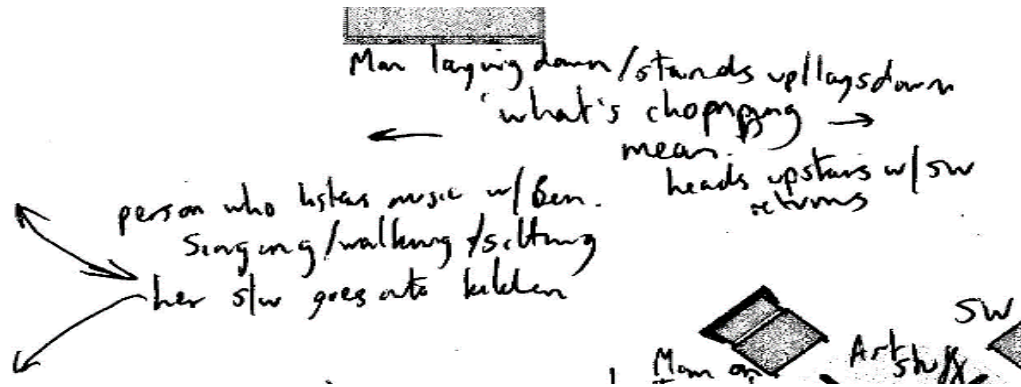


Figure 27: Fieldmap (16 July, 11:40 p.m.) depicting two inhabitants who walk regularly.

dramatic effects of this were observed when Ben was confronted with a change in his afternoon schedule – a support worker fulfilling their responsibility of writing in his communication book and offering him a drink, though not at the point expected by Ben (Chapter 5:8). Salient then is the meaning of what temporal and spatial order may mean for inhabitants, and how this may relate to regeneration. ‘Routines’ are often stressed as significant in relation to autism and profound learning disability – it relates to the ‘restricted/repetitive behaviours’ that characterise the diagnoses from the perspective of the medical model of disability (American Psychiatric Association, 2013, p. 33 & 52) – though the individual experience of spatial and temporal coherence, as well as the opposing phenomenon of change, may be less understood. Ridout (2017, p. 53) states that ‘a general understanding of what “being autistic” means has a devastating impact on the well-being of many individuals’, as generalised training means generalised approaches to support; ‘what is parasitical to one autistic person may be harmonious for another’ (Rourke, 2017, p. 142). The time-space routines of Ben had significance as they not only allowed him to be comfortable and safe within his day-to-day pursuits, but they also enabled him to step outside the strict conformity of his schedule and engage with supports workers in ways that he often found intensely challenging (Chapter 5:5), such as prompting discussions about curries (lifeworld notes, 8th April). *Regeneration* was experienced by Ben within the security of previously lived time and space, providing the physical and psychological rest that are necessary for personal and social development.

7.5 At-easeness

An aspect of formal culture considered in the literature review (Chapter 2:3) was that of intervention – how support workers are trained to engage with inhabitants – which, in the UK, is predominantly Positive Behaviour Support (PBS) (this was the case at the participating service). Training in this regard directs support workers’ perspectives on to understanding negative aspects of inhabitant behaviour so that they can promote more appropriate skills and strategies for everyday situations, though research into such approaches has varying results (see Bowring et al., 2020; Hassiotis; et al., 2018). Evidence from Ben’s

experiences at the day service demonstrate an interesting role reversal in relation to PBS and interventions in general, in that he has worked to develop an understanding of support worker actions and communication in order to promote more appropriate behaviour in them. Ben had adequate skills for his day-to-day pursuits though the support worker was the unknown factor. Ben adapted his actions according to the relationship he had with them and how he expected them to act, seeking to ensure polite modes of interaction and engagement (Chapter 5:3). This could be seen to suppress at-easeness as Ben had to 'partake in roles and behaviours' in order to 'reassure and guide the guest' (Seamon, 1979, p. 83), such as when he waits for support workers to pay and provide his membership card at the gym reception, before doing it himself if they are unsure as to what to do (lifeworld notes, 15th April). Where at-easeness was evident was in the longer standings relationships that Ben had with support workers, where etiquette had mutually formed and each could trust the other to act accordingly. In this regard, the positions and roles that develop in service culture are not as defined as intervention research might assume, with autistic people with profound learning disabilities seeking to establish what is courteous in their day-to-day situations, while support workers may choose more normative modes of civility and communication.

It may be argued that interventions are incongruous with the fostering of at-easeness as they seek to change or adapt inhabitant behaviour, challenging the very essence of at-easeness which is to be yourself and 'fear no repercussions; he can be as foolish, negative, or loving as he wishes' (Seamon, 1979, p. 83). Suggested in the literature review (see van Oorsouw et al., 2009) however was that interventions may have a more positive impact if aimed at improving support worker behaviour, as opposed to inhabitant, and this was supported by the results of research aimed at encouraging reflective practice within support worker teams (James et al., 2013). Findings from the Hall add to this, the day-to-day communication between support workers demonstrating a culture in which they sought to gain and share understandings of how *they* should act towards inhabitants (Chapter 5:19) – how to communicate or engage with them for example – though this was at times hampered by aspects of formal culture, such as inconsistent staffing. Inhabitants had a great deal to teach support workers and this required their time and consideration and the subsequent opportunity for support workers to share what is learnt. At-easeness was experienced by both support workers and Ben when they were comfortable that their actions and habits were expected and welcomed by the other (Chapter 5:5) and this was epitomized in the delicate interaction at the bowling alley each week:

*She (support worker) says 'we will do your book when we get back' but
Ben looks at her with his bag in his hand. She says 'oh go on then' and
Ben takes out his small diary book.... She makatons and vocalises to Ben*

asking 'has Ben been in a good mood?', he nods at her and she writes. He watches closely... Ann finishes then reads the writing back, talking through the day they have had, pointing to each line with her pen as she goes (lifeworld notes, 12th June).

7.6 Warmth

'Use is one quality prerequisite for warmth' (Seamon, 1979, p. 85) and so it can only develop over time, as people care for the space that they are part of. For new comers though, the space can project warmth immediately for it has been embedded in the atmosphere of the place. Evidenced in the Hall was a distinct concern for its space and this emanated from the day-to-day use of its inhabitants. It was at times hectic and crowded, yet it was this shared activity – guided by the Hall's spatial customs (Chapter 5:12) – that brought a vivid buzz to its proceedings. Inhabitants could enjoy its space, just by being there, through the people and life that surrounded them:

...the man (inhabitant) takes some slippers out of his locker and his support worker helps him put them on. He then walks around the room and holds out his hand towards each support worker and me, we all touch it gently (ethno notes, 16th April).

As Johnson, Douglas, Bigby, and Iacono (2012) reported in relation to a person with profound learning disabilities, it was significant that the Hall's inhabitants had the opportunity to nurture and shape a space in ways that are important to them, including ways in which it enables them to socialise, pursue hobbies and define their own areas; this commitment reflects back on other users of the space, observed in the ways support workers sought to accommodate the personal areas of inhabitants. This is an alignment of support worker and inhabitant culture.

For Murray (2018, p. 304), learning-disability spaces, such as day centres, are central to building communities for people with learning disabilities as they are not 'ignorant of structural and discriminatory practices' found in wider society; rather, they 'have a place in the creation and development of belonging'. Similar sentiments are echoed by McCormack (2017) who emphasises the significant time it can take for people with profound learning disabilities to develop positive relationships, and that this forms through 'shared participation in social and material environments' (p.212). Day services are significant to autistic people with profound learning disabilities because they are places in which they live – they contribute their individual habits, customs and personalities and this forms cultural practices that are supportive; an inhabitant in the Hall spent time in a darkened room (ethno notes, 12th June), for this is where it feels warm to them though equally, another chose to jump on the spot surrounded by busy tables (fieldmap,

30th July, 12:20 a.m.). Formal culture may emphasise community inclusion yet it is important to acknowledge the spaces in which community is most likely to be experienced – that which inhabitants experience together, given meaning through their day-to-day lives (Murray, 2018, p. 253). Ben enjoys a fellow inhabitant completing jigsaws on the same morning each week not because he asks them to do so, nor because support workers or service managers enable the event, but because he is in a space that he shares with this inhabitant on a consistent basis. Despite the significance placed on support workers in contemporary models of service culture (see Bigby & Beadle-Brown, 2016; Humphreys et al., 2019), their roles, marked with the formal and responsive requirements of the job, means they may be less likely to initiate the everyday, personal aspects of life that foster warmth - a support worker is not going to sit down alone each week to complete a jigsaw, even though it may provide value to an inhabitant. For inhabitants in the Hall, the experience of *warmth* was possible as they had the opportunity to have and share space with one another, to embed customs and life into it that were talismans of their characters and histories.

7.7 At-homeness: an aim for harmonious day service cultures

The purpose of this chapter has been to situate the everyday practices and experiences of autistic people with profound learning disabilities, as researched in this study, within a broader understanding of day service culture, that which includes the contributions of other inhabitants, support workers and formal authorities. It did this by drawing from Seamon's concept of at-homeness (Seamon, 1979), detailing how different cultural contributions were seen to affect the experiences of the Hall's inhabitants and the support workers they shared the space with. Noteworthy is the extent to which inhabitants contributed to the service culture of the Hall and how this instigated patterns of daily life that often promoted the characteristics of at-homeness; at times, these contributions were also accepted and developed further by support workers. For example, inhabitants' contributions and dedication to the spatial customs of the Hall, including its ways of acting and interacting, were seen to foster the experience of appropriation, and this was subsequently followed and encouraged by support workers. This is a distinct benefit of day service spaces, in that inhabitants can have input: their preferences, opinions, characters and so on, can be taken in to account over the course of time. These are the principles of personalisation, for inhabitants to shape services 'to suit their personal needs' (Morgan, 2010, p. 14), through choice, autonomy and control. Such contributions were often valued and prioritised by support workers, evidenced in the ways they could disregard aspects of formal culture, such as in their use of storytelling.

A harmonious day service culture can be seen as one in which the three key contributing groups – inhabitants, support workers and formal authorities – share values. This is congruous with previous views of good service culture, namely that put forward by Bigby, Knox, et al. (2012), though it recognises that the latter two groups may make contributions that conflict with that of inhabitants. Throughout this chapter's discussion, aspects of formal culture were suggested to challenge the culture developed by inhabitants, or that shared between inhabitants and support workers, such as in its promotion of risk, inconsistent staffing, or in the positioning of inhabitants as service users (indicating that they innately require *supporting*). In day services more broadly, it was argued that such challenges can suppress the experience of at-homeness, as inhabitants must adapt within their day to day lives to the elements of culture that support workers' adopt. Ben for example had to adapt to support workers doing things for him, even though he was better skilled for the task, such as at the gym reception. Support workers in this sense are caught in between the cultural contributions of inhabitants and of formal authorities, developing practices that are often contradictory.

If day service cultures are to be harmonious, formal authorities must recognise and respond to the values and contributions of inhabitants. This is a key issue in the context of autism and profound learning disability, as the voices of related people are so often absent from research and policy (Cluley et al., 2020, p. 251; Mietola et al., 2017; Robinson & Graham, 2020, p. 3), suggesting a social care landscape that is not encouraging day service organisations to adapt according to the perspectives of inhabitants. It is clear from this research that autistic people with profound learning disabilities have opinions and thoughts on what makes good service provision, and that these are communicated, expressed and actioned in the everyday, with effects occurring over time. As has been recognised in support worker culture (Felce et al., 2002, p. 390), inhabitants similarly have their individual 'values, motivations, competencies and interests', but in sharing experiences of sociality, activity, space and time, they also create cultured ways of being together. It is argued therefore, that for formal authorities to be seen to value the principles of personalisation, there must be an emphasis on how day services can acknowledge inhabitants' perspectives to accommodate both individual and collective forms of choice and decision making. In other words, how do inhabitants, as individuals and as members of day service communities, wish to shape and define their day services? And, how are day services recognising and facilitating this?

A possible way to answer the above questions is for service organisations, and researchers, to use the characteristics of at-homeness to ask how inhabitants are experiencing the spaces of day services, and subsequently evidence how these characteristics are being promoted or hindered. As this chapter's discussion has detailed, at-homeness can be experienced on both individual and collective levels (Seamon,

1979, p.95), and is affected by the cultural contributions of inhabitants, support workers and formal authorities. In relation to appropriation for example, it was discussed how this was promoted in the Hall through areas of personal space, though also hindered through ideas and practices around risk. In asking how day services are facilitating environments and practices that foster at-homeness, there is a necessary requirement to consider, and acknowledge, the types of environments and practices that inhabitants wish to create, or be part of, as this will be key to the types of experiences they have. This will be unique to each service, relevant to the diverse inhabitants that are part of its makeup, and should, therefore, engender unique responses, through for example, the ways in which space is organised, environments are developed, training is delivered and rotas are planned. This approach draws attention to the lifeworld perspectives of inhabitants, how they subjectively experience their worlds, rather than a fixed notion of how autistic people with profound learning disabilities wish to live or socialise: what could be more person-centred?

To summarise, the characteristics of at-homeness offer a way to understand how, over time, service culture affects the experiences of autistic people with profound learning disabilities: whether the spaces in which they situate their day-to-day adult lives are in their hands, conforming to the customs and morals that are salient to their perspectives, and, whether this is hindered or encouraged by support worker and formal culture. At-homeness is 'a prime root of personal and societal strength and growth' that has '...a major role in fostering community' (Seamon, 1979, p. 71) and so service cultures that are able to cultivate its characteristics may be making the first steps to creating spaces in society that are truly inclusive of autistic people with profound learning disabilities.

Chapter Eight - Discussion

The *While* of Participation

The purpose of this chapter's discussion is to assess whether the final objective of this research had been addressed through the earlier methodological development: that is, to enable practical research processes in which autistic people with profound learning disabilities have meaningful participation. It does this by drawing from the concept of the *while* (Heidegger, 1996) as a way to consider and evaluate how the methodology affected Ben's participation, with regard to the ways he was listened to, and contributed towards its processes and outcomes. The practical realities of the research are reflected on through three areas - dialogue, analysis and design – each concerned with how, and to what extent, the researcher was able to include Ben. The methodological development was detailed in chapter three, termed 'using lifeworld fractions to think phenomenologically while doing phenomenology', with a summary in section 3.14, though below is a summary of the approach:

- An inclusive approach framed the research in order to assess and challenge forms of marginalisation traditionally inherent in research processes involving autistic people with profound learning disabilities (Chapter 3:3).
- A constructivist epistemology guided the research, meaning that the intention was to construct understandings of participants' experiences through individual interpretations (Chapter 3:8).
- The methodology drew from the principles of the third space of inclusive research (Seale et al., 2015) in which co-researchers – people in participants' social and support circles – would contribute their perspectives on the participants' experiences (Chapter 3:4).
- A lifeworld approach orientated the research towards significant aspects of participants' experiences (Chapter 3:11 and 3:12).
- Using the process of 'thinking phenomenologically while doing phenomenology, methods and theoretical focus were adapted according to what was learned about participants' experiences, the ways they were they communicated, and the ways they related to phenomenological theory.

8.1 *The while of participation*

One researcher who discussed the inclusive nature of their research is Anne-Marie Callus (2019) whose work explored the accessibility of learning disability conferences for people with learning disabilities (Callus, 2017). Callus (2019) drew from Pierre Bourdieu's reflexive sociology (Bourdieu, 1977; Bourdieu & Wacquant, 1992) to argue that inclusive researchers should 'be aware how theory informs practice, and

vice versa', calling 'for a reflexivity that is focused on the research methodology being employed, rather than on the researcher...' (p.1249). The crux of this reflexive approach is to assess whether the practical outcomes of the methodology addressed its theoretical aims by asking questions of the situations and circumstances of the study. It is 'a means of academics checking where practices need to become more inclusive, and how to go about it' (p.1258).

A way to facilitate a reflexive approach to a methodology's practical outcomes is through Heidegger's (1996) concept of the *while*, recently brought to attention in the context of inclusive disability research by Rix et al. (2020). The *while* refers to humans' inescapable being in the world in which experience, and thus participation, is always 'in the moment' (p.6). Inclusive researchers, Rix et al. (2020) argue, aim, and often claim, to facilitate participation in the *while* for disabled people, though many of the processes and circumstances of research, analysis for example, traditionally position those persons outside of the *while*, 'in an alternative arena' (p.7). And so within the practical outcomes of methodological direction exists a tension of voice and power - who is in the *while* of participation, what the nature of their participation is and how this facilitates knowledge construction. Below, Ben's participation in the *while* of this study will be explored, now able to view it as 'there' (Rix et al., 2020, p. 7) and so to reflect on how the methodology may promote or hinder participation for research in the space of autism and profound learning disability.

8.2 *The while of participation - dialogue*

The epistemological foundation of this research was constructionism, though with a constructivist perspective that aimed to focus on the 'meaning-making activity of the individual mind' (Pernecky, 2012, p. 1121). This approach meant using practices that would keep interpretations of Ben's experiences separate, such as working with Ben separately from co-researcher participants, as it was argued (Chapter 3:8) that this would enable individual dialogues with Ben, as opposed to creating a collectively constructed knowledge of his experiences. The practicalities of conducting research in this way had both benefits and drawbacks. One positive aspect was that Ben had the opportunity to be involved to greater extents than if data was sourced through collective methods, as individual researchers (myself and the co-researcher participant) could work with him on separate schedules – according to his preferences and day-to-day pursuits. For example, the co-researcher participant primarily (apart from one occasion) worked with Ben alone, while I was away from the day service. So in this way, Ben remained in the *while*, even if it was absent of myself. A drawback was that a reliance was put onto the co-researcher participant who, as a support worker of the Hall, had their own day-to-day responsibilities, meaning that at times, data

collection, and therefore participation, was halted, delayed or set to one side. This is a consequence of constructivist processes that rely on the work of individuals, as opposed to dynamic groups and so consequently, the contributions of the co-researcher participant were far less than that of the primary researcher. Furthermore, the purpose of research collectives is to draw from the expertise of participants' social and support circles (Andrews et al., 2019) – it extends the *while* of participation back in time, before the study began, to include the knowledge that has developed between participants and those close to them. Yet constructivism hindered this as it diminished the opportunity to include a more diverse collection of knowledge constructions, so while many support workers had stories to tell of Ben, or perspectives on his communication to share, their participation, and thus Ben's participation, was minimised.

Although there is evidence here of the benefits of both collective and individual data collection methods when sourcing the perspectives of autistic people with profound learning disabilities, what appeared most salient through the multi-stage process of fieldwork was the time it took for a dialogue to emerge between myself and Ben. The importance of time has been made apparent in other areas of inclusive disability research (Brownlee-Chapman et al., 2018; Liddiard et al., 2019; Olsen & Carter, 2016), for example Olsen and Carter (2016) found they were only able to listen to the perspectives of women with learning disabilities that had been raped by providing adequate time (more than funders expected) in which to develop understanding and dialogue within group discussions (p.35). Similarly within the space of autism and profound learning disability, it has been acknowledged that it is beneficial to learn from related people across large degrees of time (Bradley et al., 2015; Goode, 1994; Simmons & Watson, 2014b, pp. 151-153) as it enables the researcher to attend to 'actions, sounds and body language, but also to tempo, mood and potential significance of meaning' (Nind, 2018, p. 116). What was notable in researching with Ben was that it was not just the time spent with him in which dialogue emerged, but the *act* of repeatedly recording the minutiae of events and circumstances shared with him across time. Ben adjusting his sock, at the same time, in the same place each week (lifeworld notes, 10th June), only gained significance because it had been noted down a number of times previously – it was apparent that it was meaningful to Ben as he had committed to it on each occasion.

Cascio et al. (2020, p. 33) uses the term 'empowerment in context' to refer to researchers using the communication methods of the participants, as opposed to using methods advocated in the wider autism and learning disability literature (e.g. using talking mats when the person communicates through Makaton). With regards to Ben, whose main forms of communication were vocalisations and body language, the crux was to maintain the dialogue over the course of a repeated engagement - 'being with'

him (see Morris, 2003) and learning from him as he communicated himself over the course of time, through attentive data collection. This is perhaps a weakness of collective research processes – ‘constructionism’ as opposed to ‘constructivism’ – as it may not be as practically viable to maintain a consistent research collective that is able to systematically ‘be with’ a participant across significant amounts of time, constructing knowledge through a careful and considered dialogue.

8.3 *The while of participation - analysis*

One area inclusive researchers have struggled to practically include disabled people in the past is within analytic processes (Rix et al., 2020; Seale et al., 2015; Stack & McDonald, 2014). This has been overcome by some academics working with people with learning disabilities, such as a project with the Carlisle People First Research Team in which thematic analysis was conducted involving visual aids, plain language and colour coding (Seale et al., 2015, pp. 490-491). Such adaptations and innovations may be less suitable in the context of autism and profound learning disability due to the knowledge capacities and communicative repertoires of related people, and there are also ethical questions with regards to individual participants and the extent to which attempts to include may cause distress: for example, Ben would probably experience upset if direct questions were asked of him (e.g. through creative methods) or if his expected, day-to-day pursuits were interrupted. First and foremost, it is acknowledged that the analysis of this research was ‘undertaken beyond the original participatory site’ and therefore creates ‘a new source of participation’ (Rix et al., 2020, p. 7). Within this new site, the contributions that Ben and the co-researcher participant had made from the original site were included, mediating the *while*, though their participation was marginalised. The constructivist approach was hindered as the individual dialogues – those between myself and Ben, and the co-researcher and Ben – converged into one interpretive account. Here, it was not possible to ‘attend’ to their direct communication (see Nind, 2018, pp. 106-108) and so the power shifted to the hands of the primary researcher and this dynamic continues as this discussion is constructed. There is potential to include co-researcher participants within analysis, and to also include them in reflections of the *while* of participation (see Rix et al., 2020, p. 7); for example, the co-researcher participant may have had insight into the dialogue they had with Ben, or the practical processes of participation and the methods involved. Such methods would create new tensions as they require greater levels of participation from research collectives, and so they require consideration if they are to be facilitated within the space of autism and profound learning disability.

Even if including co-researcher participants within analysis and reflection, the marginalised position of the most significant perspective remains, that of the autistic person with profound learning

disabilities. The *while* of participation is primarily situated where the researcher or co-researcher meet the participant which for Ben, was in the everyday events of his life at the day service. The multi-stage approach (Chapter 4), involving a cyclical process of fieldwork and analysis, made a small challenge to the exclusion of Ben from analysis as its processes blurred the boundaries of analysis and fieldwork, allowing fieldwork to shape analysis and its methods, and allowing analysis to shape fieldwork and its methods. This can be understood as a dialogic process – one that ‘assumes that there is always more than one voice’ and that ‘meaning is never singular but always emerges in the play of different voices in dialogue together’ (Wegerif, 2013, p. 3) – the concerned voices being Ben, myself and the co-researcher participant. Everyday life at the day service was explored through dimensions of space and time as they had appeared significant to Ben in the *while* of participation, and this consequently affected the final analytic focus, that of place ballet (Seamon, 1979). Importantly, this research design is not tokenistic – it does not attempt to increase participation at the sake of methodological rigour – rather, it adheres to the principles of phenomenological research espoused by established phenomenologists (Berndtsson et al., 2007; Dahlberg & Dahlberg, 2019; Zahavi, 2019) – to explore phenomenon in line with participants’ experiences and a theoretical framework.

8.4 *The while of participation – design*

Research design may have the chance to expand the site of participation for autistic people with profound learning disabilities, opening space in processes of analysis and reflection, however the *while* of participation is also relevant prior to the commencement of fieldwork – in the identification of salient research topics, carrying out literature reviews, methodology development and so on. This is a question of engagement, argues Cascio et al. (2020, p. 34): how to involve community members in the creation of appropriate and relevant research that may go on to construct knowledge that benefits their lives and circumstances. In this regard, involving Ben in a multi-stage process, coupled with a bricolage (Rogers, 2012) perspective that did not require one particular theoretical or practical approach (see Chapter 3:12 and Brownlee-Chapman et al., 2018), enabled a research design that could be developed in line with his perspective and the study context. The consequence of this was the introduction of a fieldmaps method (example below, Figure 28), utilised in the third stage of the research, that had not been considered prior to the fieldwork beginning and that would have not been used without the input of Ben in the *while*. This multi-stage design can be considered a key contribution to space of autism and profound learning disability, showing as it does the potential of investigating broad phenomenon or research topics, service

culture in the case of this study, through designs that are shaped by the values and customs of related people.

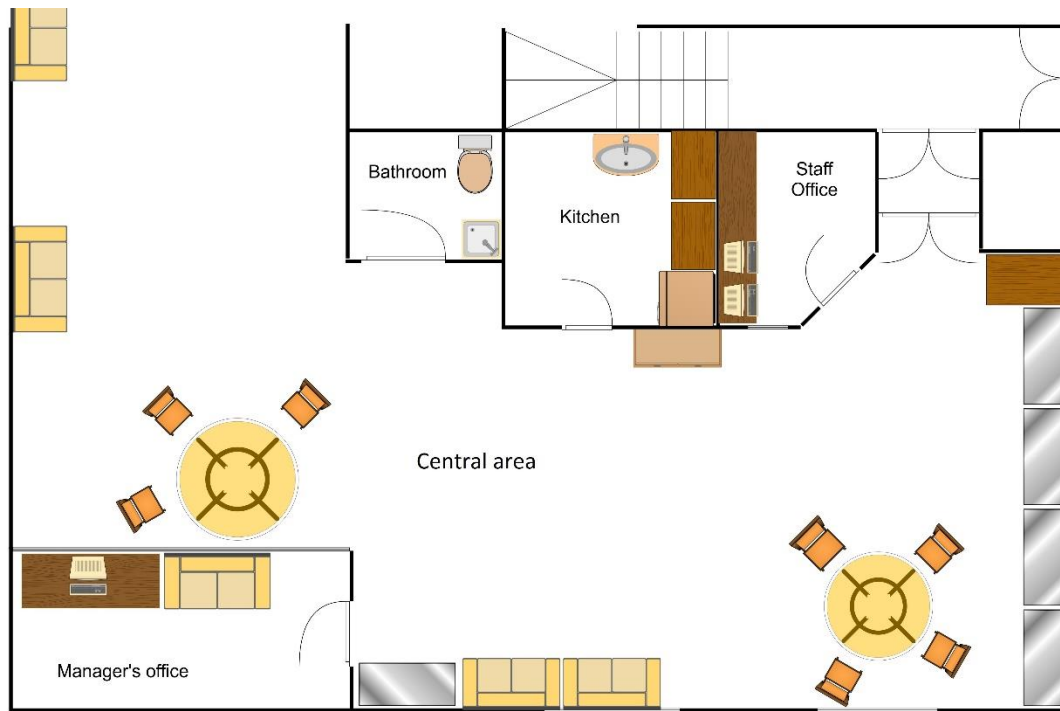


Figure 28: The Hall

8.5 Summary of the while of participation

In this chapter, the *while* of participation has been described in relation to three aspects of research relevant to the study conducted with Ben: dialogue, analysis and design. This was to evaluate the methodological approach developed as a contribution of this thesis, and to the space of autism and profound learning disability: that of 'using lifeworld fractions (Ashworth, 2016) to think phenomenologically while doing phenomenology (Berndtsson et al., 2007)'. Within the area of dialogue, a key strength of the methodological approach was that it prompted the researcher to learn of and adapt to the participant's form of communication, as well as considering how this related to the surrounding context. This is important to the process of thinking phenomenologically while doing phenomenology (Berndtsson et al., 2007, p. 270), no matter how the participants communicate, as the researcher must learn of how participants wish to express their experiences. In the case of Ben, who communicates through vocalisations and body language, it was significant that fieldwork could be conducted through repeated engagements and note-taking in his everyday life at the day service, as this is where dialogue,

and therefore, participation, was facilitated. The understanding that dialogue can be developed in this way is a notable contribution of this thesis, as dialogue is key to any form of research participation. The method, therefore, has potential for use in future research that aims to learn of the views or perspectives of autistic people with profound learning disabilities that communicate through vocalisations and body language.

A second important contribution of the methodological approach is its cyclical process of fieldwork and analysis, as this allowed Ben's perspectives to influence the study focus and design, including its theoretical scope and methods. One reason this is so critical is due to the dearth of research that has sought the views of autistic people with profound learning disabilities (Mietola et al., 2017), meaning that there is very little prior understanding of what related people view as salient aspects of their lives, or how such themes should be researched. The methodological approach goes some way to addressing both of these issues, as it first prompts the researcher to learn of how participants are experiencing a phenomenon through key fractions of their lifeworld, before providing signposts to relevant methods and theoretical perspectives. For example, time and space were significant to Ben's lifeworld, and this prompted an investigation into day service life in a way relevant to this perspective, through the scope of place ballet (Seamon, 1979) and a fieldmaps method. Participation was thus facilitated in areas of analysis and design, positioning Ben as a knowledge constructor and allowing me to ask what I could learn from him.

8.6 Reflecting on the methodology as inclusive, participatory, emancipatory or something else

At the beginning of this thesis (Chapter 1.4), the term 'inclusive research' was adopted to refer to the approach used in developing an ethically sensitive methodology to explore the experiences of autistic people with profound learning disabilities. In one sense, inclusive research is an umbrella term for research in which disabled people are 'instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users' (Walmsley & Johnson, 2003, p. 10), and includes approaches such as 'participatory' and 'emancipatory'. In another sense, 'inclusive research' is an approach in and of itself, defined over the past thirty years through research with and by people with learning disabilities (Nind & Vinha, 2014; Walmsley & Johnson, 2003), and also by autistic people (Chown et al., 2017), with its own set of principles and standards relevant to the concerned community. One reason the term 'inclusive research' was adopted in the case of this research, is because people with learning disabilities (Seale et al., 2015, p. 488) have communicated that the term is clearer than 'participatory' or 'emancipatory', and so it was deemed a more accessible and accepted term by the community that the research sought to

involve. To what extent though, does the methodology developed for and used in this study, reflect or contain the principles and aims of inclusive approaches?

Emancipatory research stems from the work of Oliver (1992) and Zarb (1992) as a means of putting disabled people 'in control of the whole process of research production' (Oliver, 1992), so to highlight, disrupt and dismantle the structures that result in disability (Barnes, 2003). Participatory research also seeks to disrupt the traditional power relations of research, though it does this through alliances, collaboration and co-production with disabled people, with less emphasis on ownership and social change (Chown et al., 2017). When defining inclusive research in a learning disability context, Walmsley and Johnson (2003, pp. 62-63) drew from both the principles of participatory and emancipatory approaches to form a kind of middle ground. Regarding the former, this related to collaboration and alliances between non-disabled researchers and people with learning disabilities, while the latter related to ownership and control of research, though with a focus on accessibility rather than full autonomy over research processes. Since then, Chown et al. (2017) have put forward a model of inclusive research which draws directly from emancipatory approaches (Oliver, 1992; Stone & Priestley, 1996), with a focus on the social model of disability, ownership of research processes, and the tackling of disabling barriers; in this regard, inclusive autism research is different to inclusive learning disability research, requiring greater involvement of autistic people. I would argue that the research and methodology described in this thesis fails to meet all of the criteria of any of these models of inclusive, participatory or emancipatory approaches, as to greater or lesser extents, they all require more involvement from disabled people across research processes. This is however, a case of the research not fitting the model, and where all of these models lack detail, is in the context of autistic people with profound learning disabilities, where ownership and control over research processes, breaking down of disabling structures (see Mietola et al., 2017), and involvement in co-production and collaboration, is significantly more difficult, or, perhaps in some cases, impossible to achieve.

It is these issues that caused Nind (2013) to cast doubt on whether any research involving people with PMLD can be termed inclusive, as it is unlikely that they will ever likely meet the criteria defined by Walmsley and Johnson (2003). So while Nind (2013) recognises the value of Ben Simmons' in depth work with Sam, a child with PMLD (Simmons & Watson, 2014b), which showed new understandings of sociality and disabling contexts in the lives of people in this group, it would, she argues, be a 'stretch' to call it inclusive, as it was done *for* people with PMLD, as opposed to *by* or *with*. In this argument, Nind is not arguing against the value of Simmon's work or methodological approach, but is instead confronting the constraints and exclusivity of inclusive models. Since, Nind has turned towards a more expansive idea of

‘doing research inclusively’ as opposed to doing inclusive research, which has at the heart of it *dialogue* (Nind, 2018, 2019; Nind & Vinha, 2014); as such, Nind (2018, p.114-115) has marked Simmons’ dialogue with Sam as a sign that he was doing research inclusively.

Detailed in this chapter, were the ways in which dialogue was facilitated with Ben during fieldwork, through many of the methods that Simmons had done so with Sam, including close and extended observations and engagement within his day-to-day circumstances, and detailed note-taking of his communication and contexts. It was also described how the methodological approach enabled the dialogue between myself and Ben to influence the research’s direction regarding methods and theories, which affected how the research was subsequently carried out. The focus on space and time in the Hall had not been of interest prior to, or during the early stages of fieldwork, and it was only recognised as such through the considered dialogue which I developed with Ben. This is a novel and valuable finding, that dialogue with autistic people with profound learning disabilities can and should, contribute to the ways important factors and circumstances in their lives are researched, which in the case of this study was day services and their cultures. I would argue that this is evidence of research being done inclusively, as Nind might also, and would suggest that, as such, the methodology of ‘using lifeworld fractions to think phenomenologically while doing phenomenology’ can enable researchers to practice research inclusively with autistic people with profound learning disabilities. Until models of inclusive, emancipatory and participatory research take into account the views, circumstances and abilities of autistic people with profound learning disabilities, this will have to do.

Chapter Nine – Conclusion

This thesis began by detailing two aims, each with a group of objectives (Chapter 1.3): one aim related to research into day service culture from the perspectives of autistic people with profound learning disabilities, another related to the development of a methodological approach for researching the experiences of autistic people with profound learning disabilities. Both aims and their related objectives have been addressed throughout this thesis and through an empirical study, and so this concluding chapter will explore the contributions that have been made. This will include the implications the thesis has for future research and practice, as well as its limitations. The discussion begins with consideration of the research aims relating to day service culture, followed by those which related to a methodological development.

Contributions, implications and limitations

Day service culture

9.1 Key contributions

The first objective of this study aim was to establish current understandings of day service culture in relation to the customs, contributions and perspectives of autistic people with profound learning disabilities. The literature review highlighted a dearth of research in this specific area, though there were investigations into service culture (e.g. Bigby, Knox, et al., 2012) that had relevance to the ways in which cultures form through the contributions of staff and formal authorities. Drawing from Black et al. (2018), it was possible to suggest that inhabitants contribute to day service culture within their everyday lives, and that this forms practices and customs that they and support workers follow. The empirical investigation into day service culture subsequently supported this view, finding that the inhabitants of the Hall had developed and contributed to a culture with conventions and procedures, and that this affected the ways in which inhabitants and support workers acted and interacted. A key contribution of this thesis, therefore, is a new concept of day service culture: one that recognises three contributing groups – inhabitants, support workers and formal authorities (e.g. managers, policy makers and researchers) – each having their own values and interests that interrelate and influence how day services run day-to-day.

Focusing on the roles of inhabitants within service culture, it can be said that there exists a relationship between the subjective ways they experience their everyday, and the practices that they value and promote. For Ben, aspects of embodiment, space and time were an eminent part of his lifeworld, and so he had developed ways of acting and socialising at the day service that were congruous

with this outlook. This included establishing areas of space as his own, maintaining a schedule that reassured him, and creating forms of civility between himself and support workers. In establishing such practices, Ben was exerting choice and control, and experiencing himself as an independent person, as well as part of a community. The consequence of being part of a community though, is that Ben also experienced practices that were indicative of the wider culture of the service, such as on occasions when he was overly supported, at the gym reception for example. These were not merely support worker practices, for Ben acted according to them, as the *supported*, demonstrating how culture also influenced his practices and conduct. In many circumstances, the broader service culture worked fine for Ben, he could use the gym in the above instance, and so there was no incentive to change the culture according to his experiences. On occasion though, Ben was confronted with inadequate practice, specifically, the temporally related action of filling in his communication book and the collection of a drink, and, as this was experienced with great apprehension, he communicated that this was not ok, and this garnered a reaction from a number of support workers. This is an example of how, over time and according to their experiences, autistic people with profound learning disabilities can change the practices and culture of support workers: by communicating what they feel is appropriate or not, and by acting with enthusiasm, dismay, acceptance, or interest towards particular practices. A second key contribution of this thesis is thus: that autistic people with profound learning disabilities contribute to service culture within the everyday, through the ways they communicate and in relation to their subjective perspectives. They are also part of wider service cultures, experiencing their make-ups and customs, those which are developed through the contributions of other inhabitants, support workers and formal authorities.

Moving to the everyday more broadly, the thesis provided understanding of how inhabitants as groups create cultural customs that guide their day-to-day lives, as well as those of support workers. This was grounded in aspects of space and time, showing how a diverse group of people can make space work for them in ways that are compatible with their varying roles, interests and responsibilities. These were culturally formed ways of acting and interacting within the space of the Hall, rather than a prescribed guidance from the service as an organisation. This culture not only allowed day-to-day events to proceed with a sense of expectancy, but also promoted the values and customs of inhabitants, as established over the course of time. The space hierarchy was a prominent representation of the inhabitants' contributions, containing within it accepted ways of acting and expressing relevant to their dispositions and schedules, rather than those of support workers. It is also notable that support workers were at the bottom of the hierarchy, adhering to its principles and accepting of its consequences. This was one way support workers recognised and promoted inhabitant culture; another was through methods of storytelling, teaching each

other about the ways in which inhabitants have shaped the history and character of the Hall. This cultural practice is an example of support workers disregarding aspects of formal culture, namely to maintain a professional service-service user relationship, and instead creating their own customs that maintain the social life and history of the Hall, and conserve the cultural contributions of inhabitants. Such aspects of everyday life are significant in creating welcoming environments, improved working practices and positive relationships between the inhabitants and support workers of day services. It is a response to the transient nature of support workers, and the efforts that inhabitants have made to shape the day service. Understanding the relationship between the everyday and service culture in this way is a third contribution of this thesis, as it challenges previous ideas that positive service cultures exist when there is harmony between support worker culture and formal culture (see Bigby, Knox, et al., 2012; Bigby, Knox, Beadle-Brown, et al., 2014; Humphreys et al., 2019). Formal culture can have contradictory values, for example in its emphasis on the risks and autonomy of inhabitants, that can lead to contradictory practices, such as support workers promoting but controlling inhabitants' personal space. It may, therefore, not always hold values that are congruous with those of inhabitants. It can subsequently be suggested that a positive service culture requires a harmony between the three contributing groups, inhabitants, support workers and formal authorities, though prioritised within this should be the values and customs of inhabitants, specific to individual day services and in relation to those inhabitants that are part of their cultures.

Day service cultures are important in the lives of autistic people with profound learning disabilities because they represent a guiding aspect of adulthood that affects their day-to-day environments, what they are and are not allowed to do, how people engage with them and so on: in other words, the experiences they have. This view was found across Ben's experiences, as well as in relation to the other inhabitants of the Hall. It is important to recognise though that inhabitants' experiences are not isolated from one another's, rather, that they are experiences shared through relationships developed in time and space, and through activities, expressions and customs. Day services in this sense, are places in which autistic people with profound learning disabilities can experience community, as it roots their adult lives to a space that they have the opportunity to shape alongside companions, acquaintances and peers. This is a contribution to an understanding of community in relation to autistic people with profound learning disabilities, highlighting the importance of participation in shared spaces, across time, and in ways that promote individual outlooks and interests, as well as those formed together through shared cultural practices.

9.2 Implications

To create day service cultures that are harmonious and that adhere to the values of inhabitants, day service organisations have a responsibility to recognise, promote and respond to such values. It can be argued that this is not only consistent with the principles of personalisation – for inhabitants to shape services according to their needs and interests (Morgan, 2010, p. 14) – but that it should be seen as fundamental to services adhering to said aims. This perspective recognises that, as Ben did, autistic people with profound learning disabilities have views and opinions on how day services should function and evolve. Consideration should include the types of environments that are developed, how the space is used, the temporal structure of activities and space, and the ways in which support workers act and communicate. This process is to move away from broad notions of how autistic people with profound learning disabilities want their day-to-day lives structured and organised (see Ridout, 2017, p. 53; Rourke, 2017), as based on their positions as ‘service users’, or their diagnostic labels, and towards spaces and practices that are shaped by inhabitants perspectives: as individuals and collectives.

A potential way to assess and develop harmony in day service cultures is for service organisations and researchers to use David Seamon’s concept of ‘at-homeness’ (1979). This represents a valuable tool as it relates to the everyday, where autistic people with profound learning disabilities contribute to service culture, and because it is concerned with ways of experiencing that are central to personal development, security and wellbeing. The five characteristics of at-homeness are categories to explore how inhabitants are experiencing a space, its people and its practices, and to investigate how this relates to aspects of culture, including the contributions of inhabitants, support workers and formal authorities. These characteristics have value as they necessarily put inhabitants first, requiring consideration and understanding of their subjective experiences, before practices, approaches and environments can be assessed and adapted. Understandings of inhabitants’ experiences have potential to be used within training, to develop support plans, within communication strategies, to develop empathetic support worker practices, or in designing day service layouts; at-homeness could therefore could be a tool to achieve person-centred practice and develop day services that respond to the particular individuals they support.

A further reason that at-homeness has potential in promoting harmonious day services cultures is that its characteristics relate not only to individual experiences, but also to that of collectives, meaning that it can be used to explore the relationship between day service communities and their related cultures. This corresponds to the findings that autistic people with profound learning disabilities experience community within day services, creating customs and practices that contribute to, and are indicative of,

service culture, but that also experience the effects of service culture developed by support workers and formal authorities. Broad customs within day services may create positive experiences for inhabitants, for instance the gatherings observed within the Hall where its activity and social atmosphere had value for Ben. It should be the responsibility of service organisations to evaluate whether broad practices have a positive impact on inhabitants, and the characteristics of at-homeness provide a scope to assess this. It may be that they foster experiences of rootedness, such as in the mentioned gatherings, or that they promote appropriation, such as inhabitants having personal areas. Similarly, broad practices may hinder the possibility of at-homeness and thus require attention, the exacerbation of risk being a principle example highlighted in this research. Also relevant to this process is recognising that support workers may develop practices discordant with aspects of formal culture, but that foster aspects of at-homeness for inhabitants. Storytelling in the Hall had such a function, and that appeared to have a wider possible benefit if recognised and responded to formally, for example by recording or documenting every day, meaningful experiences, expressions and activities of inhabitants, so to maintain and promote their contributions to the service's community and character.

In arguing for the potential of at-homeness in the consideration and development of harmonious day service cultures, it is acknowledged that this proposal requires further empirical investigation. Understanding is required in the following areas: first, how service organisations can use the characteristics of at-homeness to understand inhabitants' experiences, and subsequently respond to them through changes to their own practices. Second, how support workers might be able to recognise the cultural contributions and values of inhabitants within the everyday, so as to promote and establish them within wider service culture. Third, how the physical space of day services affect place ballets, and the possibility of at-homeness. This should include consideration of crowding and movement, and how inhabitants and support workers are challenged or enabled by space and its related practices. Fourth, how day service organisations may better document, record and promote the communities that autistic people with profound learning disabilities create and live within, and the ways that this may help to foster the experience of at-homeness. Fifth, exploring further what aspects of support worker and formal culture are valued or disliked by autistic people with profound learning disabilities, with reference to their experiences of at-homeness.

9.3 Limitations

This study provided an insight into the everyday life and culture of a single day service. Service cultures are, by their nature, unique to individual organisations as they develop on a number of levels and in

relation to the motivations and interests of inhabitants, support workers and formal authorities. The study findings may therefore, not reflect the particularities of other day service cultures. Inhabitants within the Hall were contributing to service culture and this was guiding some day-to-day customs and practices. It may be that this represents a positive service culture when compared to other day services, who might have more restrictive practices or have less regard for the input of inhabitants. As detailed in Chapter Seven's discussion, some practices or customs in the Hall had been reported elsewhere, such as the exaggeration of risk by support workers, or the valuing of space by inhabitants, so there was evidence that the culture was not unique, though it will inevitably have some unique features. Understanding day service cultures in other contexts is thus a point for further empirical investigation, with particular concerns for the roles and perspectives of autistic people with profound learning disabilities.

Contemporary day services provide support in a variety of ways. The participating day service, for example, supported people at the physical building, as well as to go into local areas from the building, such as when Ben goes to the gym. Other inhabitants merely use the building as a meeting spot, before leaving for the day to pursue their particular interests. Some people do not visit the day service building at all, instead being supported through outreach methods, or from their homes. These types of support are indicative of the developing social care landscape in which day services are responding to the principles of personalisation and community inclusion. As such, the findings from the Hall and Ben's experiences of space and time, may have less relevance to some autistic people with profound learning disabilities, those who are primarily supported outside of day service buildings. It is important to note that such people will still contribute to day service cultures within the everyday, through the way they act and interact with support workers, expressing their values and interests. Similarly, broader day service culture values will affect how support workers engage with them, the types of activities they promote and so on. So, once more, this is a point that deserves research interest, specifically in regards to how autistic people with profound learning disabilities are able to contribute to service cultures when they do not access a central service space.

A final limitation of the study is that it explored the lifeworld perspective of a single participant, that of Ben. It could be said that Ben's experiences are not reflective of autistic people with profound learning disabilities in general, for example many will not seek the security of such a particular schedule. While this may be the case, Ben's experiences provided a guiding perspective on how to research the day service more broadly, and his experiences of space and time were clearly not unique to him, as there were related customs within the Hall that both inhabitants and support workers valued and participated in. Even when outside of the Hall, at the gym for example, Ben had aspects of experience that were related

to his position as a *service user*, such as having menial tasks done for him, and this is suggestive of broader cultural practices that many inhabitants experience. Moreover, the importance of space and time evidenced in Ben's experiences is not merely subjective, for it represents foundational aspects of the lifeworld that has relevance to any human consciousness. The spaces in which we spend our day-to-day lives have a significant effect on our lifeworld experiences, including the places we work, the towns we inhabit, the parks we visit and the homes we live in: they are fundamental to who we are. So, although it is not appropriate to understand Ben's experiences as broadly representative of other autistic people with profound learning disabilities, there are aspects that are relevant to the life-conditions (Kraus, 2015) he shares with them; particularly and importantly, his perspective of day service spaces.

Methodologies for researching with autistic people with profound learning disabilities

9.4 Key contributions

The methodological development began with an initial objective to explore, and take into account, the ethics of developing research for people considered to be autistic with profound learning disabilities. To do this, it was first necessary to establish who was being referred to when using such terminology. A literature review suggested there was no epistemic reason to separate the terms 'autism', 'severe learning disability' and 'profound learning disability', when considering research for people with complex needs. Subsequently, it was argued, through consideration of the representation of related people, that it was also ethically unjustified to separate the terms. Consequently, the phenomenological concept of lifeworlds and life-conditions (Kraus, 2015) was drawn from to propose a space of 'autism and profound learning disability', one that recognises the shared 'material and immaterial circumstances' of people with complex needs related to the terms autism, severe learning disability and profound learning disability. This is a key contribution of this thesis that seeks to establish and promote ethically sensitive ways of researching with autistic people with profound learning disabilities, in such a way that their perspectives and voices gain recognition in academic, social and political life.

Drawing from the third space of inclusive research (Seale et al., 2015), it was proposed that an appropriate way to research with autistic people with profound learning disabilities is to form research collectives with participants and their social and support circles. In regards to this, issues were raised relating to the double empathy problem (Milton, 2012a) and inclusion phobia (Goodey, 2015), specifically that it may be ethically insensitive to have groups of people who do not identify as autistic, or with a learning disability, constructing interpretations of the experiences of autistic people with profound learning disabilities. It was contended that this issue could be addressed with a constructivist approach,

one that aimed to facilitate individual dialogues between participants and members of research collectives. Reflecting on the practical outcomes of this approach, it was contended that dialogue was facilitated with Ben through repeated engagement and attentive data collection. This contribution is a method for researchers to meaningfully engage with autistic people with profound learning disabilities, to learn of their experiences and perspectives in different day-to-day circumstances and in relation to the particular ways they communicate.

Lifeworld fractions (Ashworth, 2016) have previously been identified as a tool for inclusive autism research and learning disability research (Andrews et al., 2019; Hodge, 2008). What this thesis adds is a recognition and demonstration of their potential for highlighting aspects of experience significant to participants, so that researchers can identify relevant theoretical perspectives and research methods. This is a key contribution as it enables researchers to work with autistic people with profound learning disabilities to identify salient aspects of their lifeworlds; it is, therefore, a tool that can facilitate inclusive research practice, as it asks researchers to respond to participants' circumstances and perspectives. This is particularly useful in the space of autism and profound learning disability, as there is such little understanding to draw from when establishing research focuses or theoretical outlooks that are relevant to related peoples' experiences.

Strengthening the contribution of the fractions method is their positioning within the process of thinking phenomenologically while doing phenomenology (Berndtsson et al., 2007). This was accomplished by taking the complex approach described by Berndtsson et al. (2007), and grounding it in a clear multi-stage process that uses lifeworld fractions as a guide to phenomenological theory relevant to participants' experiences. The consequence of this is that researchers can learn how to research phenomena through approaches and methods that are appropriate for the research context, and pertinent to participants' perspectives and the ways they communicate experience. This has apparent use in the space of autism and profound learning disability, demonstrated through the ways it enabled research into the everyday within the Hall from the perspective of Ben. The approach does also however, have applicability for any researchers concerned with explicating phenomena through a phenomenologically informed approach. Its strengths can be summarised as follows: first, it is an adaptable approach, meaning that it can be used in diverse research contexts and with participants of varying circumstances and dispositions. Second, it is an accessible approach, as the fractions are presented in an accessible manner and do not require an in-depth, prior understanding of phenomenological theory. Researchers can use the fractions according to the circumstances: this may be that they are relatively new to qualitative research with a limited amount of time to conduct a study, and

therefore they might only use the fractions on a base level, as described by Ashworth (2006, 2016), to provide a focus to their methods that is relevant to their participants' experiences. In contrast, they can also be used in research projects with more extensive aims, as detailed in this thesis, providing a framework for researchers to identify theoretical concepts that are relevant to their study. Third, the researcher must seek to learn from the participants - utilising methods that are appropriate to the ways they communicate their experiences within their day to day contexts - thus the approach prompts ways of researching that are ethically sensitive to different lifestyles and cultural practices. Third, the cyclical process of fieldwork and analysis leads the researcher to develop an in depth understanding of their data and its relationship to the study context and participants; in doing so, the researcher is in a position to analyse and consider data with confidence and insight. Fourth, the approach develops the researcher's theoretical and practical skills as they learn of phenomenological theory and its relevance in the application of empirical research and everyday contexts. Fifth, the approach adheres to the principles of phenomenologically informed research espoused by established phenomenologists (Berndtsson et al., 2007; Dahlberg & Dahlberg, 2019; Zahavi, 2019) – to explore phenomenon in line with participants' experiences and a theoretical framework.

9.5 Implications

In establishing a space of autism and profound learning disability, the intention is to form a body of knowledge relating to the lives and perspectives of people with complex needs, those considered in relation to the terms autism, severe learning disability and profound learning disability. This knowledge should be constructed with the input of autistic people with profound learning disabilities, and concern themes and areas that they have identified as important. To do this requires researchers to develop and establish appropriate and effective ways of working, with regards to specific research areas and with consideration of how autistic people with profound learning disabilities could best participate. Reflecting on the *while* of participation (Heidegger, 1996; Rix et al., 2020) can provide understanding of the value of different research approaches and methods, highlighting the ways in which participants can engage in difference research processes. The space of autism and profound learning disability concerns research development, practice and findings in relation to both the academic field of autism, and of learning disability, and it is hoped that researchers who have traditionally focused on one or another, can recognise the importance of attending to the shared voices and perspectives of people with complex needs. The adoption of the life-conditions (Kraus, 2015) perspective can bridge this divide, and in doing so, research

and policy can be developed according the views and circumstances of autistic people with profound learning disabilities.

The methodological development contributed in this thesis has shown to have potential in aiding researchers to develop studies through the perspectives of autistic people with profound learning disabilities. It does, therefore, have application in the space of autism and profound learning disability, for establishing theoretical perspectives or research methods that are relevant to different circumstances, and for providing a way for participants to be involved in different research processes. There could also be benefits in exploring how research collectives can be involved to greater extents, with the fractions representing an accessible view of lifeworlds that may help to facilitate their thinking phenomenologically while doing phenomenology. The process provides a way to establish dialogue with autistic people with profound learning disabilities, one situated in the everyday, so if used more widely, can help to challenge views that related people cannot represent themselves in academic and societal processes (see Chapter 4.1).

Using lifeworld fractions to think phenomenologically while doing phenomenology also has use outside of the space of autism and profound learning disability, for researchers seeking to investigate human experience from the perspective of research participants. In providing giving the methodology a theoretical grounding (Chapter four) and illustrative guide (Chapter five), this thesis serves as a tool for researchers to conduct phenomenologically informed research from design to analysis. This requires flexible, reflective and creative ways of working and a willingness to learn from participants, so one can respond to the particular ways that they experience an event. It is expected that researchers that utilise the approach will establish novel and innovative ways of working that are appropriate for particular research contexts and the circumstances of specific population groups, and this has the potential to ethical research practice in a variety of research fields.

9.6 *Limitations*

This study involved only one primary participant, Ben, so it unclear as to how the methodology may scale when seeking to work with a greater number of participants and within larger research collectives. To learn of Ben's experiences, the approach was time-intensive, but this is part of working with autistic people with profound learning disabilities in ways that are sensitive to their perspectives and day-to-day circumstances. To use the methodology to research with a greater number of autistic people with profound learning disabilities will therefore, require consideration of time constraints, but this is not unique to the methodology, rather a reflection of the time it take to create meaningful dialogue with

related people. Although it would also require time to co-ordinate larger research collectives, their contributions to data collection can help to learn of participants' experiences more efficiently, and so their participation may have wider benefits to the methodological process. Of course, this requires ethical consideration, such as the possibility of researchers taking part in a paid capacity or having an opportunity to produce and author relevant publications. These are considerations for future research development in the space of autism and profound learning disability, with relevance to the scale and circumstances of individual studies.

As a methodological development in and of itself, the approach may have limited applicability in the following contexts: first, where there is considerable prior knowledge of a phenomenon that can guide a specific research focus and related method. Second, where access to a research context is limited, for example Andrews et al. (2019) a situation in which ethical barriers restricted the possibility of directly engaging with autistic participants. Narrative approaches (e.g. McCormack, 2017; Ridout, 2016) or parent-led interviews (Andrews et al., 2019) may have greater applicability in such instances. Third, when researching over the course of multiple stages is not possible – this may relate to the circumstances of the researcher, research context or the choice of participants.

9.7 Thesis conclusion

This thesis has addressed its two key aims: first, it has explicated day service culture from the perspectives of autistic adults with profound learning disabilities, showing that inhabitants develop and contribute to culture in the everyday, creating customs that guide day service life. These findings highlight the ways in which autistic people with profound learning disabilities exercise autonomy and choice in their day-to-day adult lives, changing space and its practices to create environments and social relationships that are congruous with their values and perspectives. It is contended that to create harmonious day service cultures, it is vital to recognise the cultural contributions of autistic people with profound learning disabilities, and it is proposed that this can be achieved through Seamon's (1979) concept of at-homeness, as this relates to the everyday spatial experiences of individuals and collectives.

The development of a methodology, 'using lifeworld fractions (Ashworth, 2016) to think phenomenologically while doing phenomenology (Berndtsson et al., 2007)', addressed the second aim of this thesis, as it detailed and demonstrated an approach to explore the experiences of autistic people with profound learning disabilities. It holds distinct value in that it can help to increase the practical participation of autistic people with profound learning disabilities within research, particularly in regards to directing researchers to methods and approaches that are salient to their experiences and

circumstances. The approach demonstrates that autistic people with profound learning disabilities have insight and perspectives that, if given attention, can enable researchers to create more inclusive academic practices.

In tendering this thesis for public consumption, may the words and images contained within its chapters offer some insight into how people with complex needs, those related to the space of autism and profound learning disability, may come to be better represented in research. Their day-to-day contributions shape day service cultures and their related communities, and so too should they shape the academic, social and political discourses that affect their lives.

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Appendices

Ethics information sheets

The ethics process was complex due to the study involving people thought to lack capacity to consent to participate, as well as it being based in a busy day service for autistic adults, and as it sought to recruit participant 'co-researchers'. This meant consideration had to be given to the ways in which different people would be participating in the study, from Ben's extensive involvement, to those support workers who were merely part of the everyday activity of the day service. Consequently, nine information sheets were designed for use in the study, each giving details relevant to different types of participation. Five consent forms were also created for those people involved with greater degrees of participation, such as Ben's day-to-day support workers, the co-researcher and his parents. Provided below are two documents relevant to Ben's participation: an accessible information sheet used to explain the research to Ben, and an information sheet given to his parents to explain the research and to seek their participation as a personal consultee of Ben. In line with recommendations of the ethics committees, Ben's capacity to consent to participate was assessed by senior staff at the day service, due to their knowledge of how to engage with him and understand his communication.

Accessible Information Sheet

Taking part in research.



This is Ned. Ned is a Researcher.

[IMAGE OF PARTICIPANT] Ned would like to research with you.



Ned will listen to you and your support workers.



Ned will join in with your activities.



Ned will write down what you do at the service.



Ned will talk to your family and support workers

about what you do at the service.



Ned will read your reports.



You can talk to Ned if you want.



Ned will stop if you want.

Participant's Personal Consultee Information Sheet

Study Title: The Lifeworlds of Autistic Adults with Profound Learning Disabilities
Transitioning to Adulthood: An Inclusive Ethnographic Case Study

Invitation and Brief Summary

I would like to invite your son/daughter to take part in this study. *Before you decide whether or not they would like to take part, it is important for you to understand why the research is being done and what it will involve.* The purpose of this study is to learn about the experiences of young (aged 18-34) autistic adults with profound learning disabilities within day support services. It aims to understand how the period after leaving school – the transition to adulthood – is experienced by this group of people.

Your son/daughter's participation

If you decide that your son/daughter would like to take part in the study, their participation will involve:

- Ned Redmore observing them whilst at their day service (approximately between 10am and 3pm) and making notes relating to their experiences. This will take place on 4-5 weeks (mon-fri) across 1 year.
- Ned Redmore copying documents (e.g. risk assessments) that relate to how the service represents their views and perspectives.
- A member of support staff creating notes relating to their experiences at the service. This will take place on 24 days across 1 year (approximately between 10am and 3pm).
- Their annual service review meeting being audio recorded.
- Archive material (e.g. photos) relating to their experiences at the day service being submitted by a family member.

Your role as personal consultee

If you decide to be your son/daughter's personal consultee, you must consider whether they would like to take part in the study or whether doing so might upset them. In doing so, you should consider your son/daughter's past and present views on what the research might mean to them. If at any stage you believe your son/daughter would not like to remain in the study, it is your responsibility to advise Ned Redmore. Further guidance on the role of a personal consultee is available at www.hra.nhs.uk.

What are the possible benefits of taking part?

- A better understanding of your family member's experiences of support.
- The possibility of improving how your family member's service responds to their perspectives.
- A chance to provide a small contribution to a wider discussion on how society understands autistic people with profound learning disabilities.

What are the possible disadvantages and risks of taking part?

- A chance that you may revisit difficult memories or experiences.
- You may feel concern or anxiety that the research will cause problems for your family member.
- A small possibility that the time commitment could result in stress.

Further supporting information

What if something goes wrong?

Although it is anticipated that participating will not impact on your son/daughter, this will be discussed with yourself and senior service staff to ensure that their support is not affected. Throughout the course of the yearlong study Ned will ensure that he is available to discuss any queries or difficulties that you may have, and to assist or make arrangements if necessary. If you believe that the research is causing your son/daughter undue problems, you have the right to withdraw your son/daughter's participation and without giving a reason.

Taking part and your right to withdraw from the study

- If you agree that your son/daughter would like to take part in the study, please complete the attached consent form and return it by email to XXX.
- You have the right to withdraw your son/daughter from the study at any time during their participation and without giving a reason.
- You have the right to ask for data relating to your son/daughter to be removed up until November 2019.

Confidentiality

If you agree to participate, your personal information (as recorded on the consent form) will be securely stored in a digitised format on the Open University computer server (encrypted) and not disclosed to anyone except the study supervisors. This will be kept until the publication of the related research thesis. The hard copy will be shredded after digitisation.

In relation to the collected research data, any details that could identify your son/daughter will be anonymised through changes of names and any identifying information (e.g. specific locations or events), and blurring of pictures. All project data will be kept in line with Open University Policy: securely (encrypted) on their electronic servers until the first related publication of the research, at which point it will be deposited in the Open Research Data Online (ORDO) so it can be used for future research and learning (for up to 10 years). Pseudonyms will be used in any publication that come as a result of the research. Ned will abide by the principles of the Data Protection Act 1998 and the General Data Protection Regulation 2018.

Any information you disclose during the research will be confidential, unless you report something that suggests that you or another person could be at risk of harm. This would be discussed with you before any other person is notified. Similarly, Ned has a responsibility to report any incidents or actions that could be considered a safeguarding concern, such as abuse or neglect. This would take place through a senior member of service staff, or alternatively the Open University Safeguarding team (XXX).

Who is organising and funding this project?

This study is part of a PhD research project funded by The Open University and based at their Faculty of Wellbeing, Education and Language Studies.

Who has reviewed this study?

This study has been reviewed and given a favourable opinion by the Coventry and Warwickshire Research Ethics Committee. This is an independent review of the research to ensure the research will protect the dignity, rights, safety and wellbeing of all involved.